Virtue Ethics as the Basis of Aotearoa New Zealand's Response to Crispr Cas-9: A Framework and Defence

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Abstract

Gene editing in humans has long been a topic of ethical debate. Although gene editing techniques have been in development for many years now, the emergence of a faster and cheaper method, CRISPR (Clustered, Regularly Interspaced Short Palindromic Repeats), is increasing the urgency of such debates. CRISPR has been recognised as a 'game-changer' across the scientific community and in commercial spheres, offering potential for life-saving treatments and even the eradication of serious diseases in humans. However, the speed and affordability of CRISPR lends it towards widespread use outside of laboratory settings, and is outstripping the pace of the current regulatory policies on gene editing applications. There remains a concerning gap between CRISPR technology and policies regulating its use in an ethically sound, safe manner, not only for this generation, but for generations to come. In Aotearoa New Zealand, there has not been an official review of gene editing policy in over two decades, well before the emergence of CRISPR as a major player in biotechnology. This project will compare major normative accounts of consequentialism and deontology with various accounts of virtue ethics, explaining why consequentialist and deontological processes will not be up to the task of guiding responses to ethically complex gene editing cases on their own. This work shifts the focus to decision-makers tasked with determining the most ethical course of action on individual cases pertaining to CRISPR uses in Aotearoa New Zealand. I propose a novel 'toolkit' of virtues developed from virtue ethics traditions, grounded in principles of Tikanga Māori, in combination with a casuist approach to individual cases. This approach aims to empower decision makers to consider and account for the broader aspects of such decisions. As the issues in this project concern complex and multifaceted issues, this thesis will not uncover any specific, definitive answers regarding individual issues. In fact, one of my primary concerns is that we should resist very generalised, top-down pronouncements regarding particular cases of gene editing. Rather, the framework outlined in this thesis presents a new approach to addressing such issues, one that I believe warrants further exploration.

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Introduction

In 2019, researchers at Griffiths University in Australia claimed to be on the cusp of a cure for cervical cancer using breakthrough gene editing technology, CRISPR (Clustered, Regularly Interspaced, Short Palindromic Repeats) (Irving, 2019). Using the CRISPR method on mice, scientists were able to isolate, disrupt and remove the cancer-causing genes without affecting any healthy cells in 100% of test subjects. Based on these results, there are plans to trial the treatment in humans in as early as 2024. This exciting news highlights just one of the emerging possibilities of human gene editing through technology like CRISPR.

In the following chapters, I will explain why the possibilities opening up for treatment of diseases and human enhancement through CRISPR makes setting rigid regulations increasingly difficult, and that the pace of such technological advances renders management at a legal and policy level especially challenging. In response, I propose a novel, flexible, values-based approach to such ethically difficult cases, showing why this is worth exploring. As gene editing technologies rapidly advance, into realms previously thought of as being science fiction, we must develop a new approach to managing the ethical demands of such possibilities for humans, both now and into the future.

Gene editing, particularly in humans, has long been a topic of ethical debate. Although gene editing practices and techniques have been in development for many years now, the emergence of faster and cheaper methods such as CRISPR are increasing the level of urgency to engage in such ethical debates in formulating policy and making ethically sound decisions that can adequately regulate gene editing towards the good of the general public (Caplan, A. L., Parent, B., Plunkett, C., & Shen, M. 2015). The vast potential of gene editing techniques such as CRISPR has been recognised across the scientific community and in commercial spheres, giving rise to urgent debate on the ethical, legal and economic ramifications of widespread use.

However, the speed and efficiency of CRISPR is outstripping the pace of current regulatory policies around the research practices, management and implications of gene editing, in plants, animals and in the very near future, humans. There is potential for life saving treatments and even the eradication of serious diseases. One

of the many problems with rapidly developing technology is that without adequate policy concerning the ethical issues of such practices, unbridled gene editing practices place humanity as we know it under tremendous risk of increased inequity through eugenics, carried forward through generations.

One problem to address is that current literature on the ethical challenges to gene editing indicates a lack of clear consensus on how policymakers ought to begin creating robust regulatory policy that keeps pace with the speed of such technology. Reviewing research on the ethics of gene editing reveals a concerning gap between the pace of technology development and creating regulations for applying such technology in an ethically sound, safe manner, both now and for generations to come.

As people develop the ability to alter a species - including their own - according to their desires and uses, then it is vital to examine the moral philosophical value systems that motivate this. This work offers a critical examination of the value systems that underpin ethical decision-making as it pertains to the practical uses of such technology.

This project aims to apply ethical recommendations towards the practice of gene editing through the lens of normative philosophical theories. I will focus on virtue ethics, in comparison to consequentialism and deontology and show why a flexible, values based approach is a serious contender as a normative basis for decisions on gene editing applications.

This research is important for multiple reasons, most notably including the potential ramifications of gene editing that will extend beyond the current generation. Creating policy that regulates the use of such techniques should be grounded in critical thought and a clear value system directed towards furthering human flourishing both now and in generations to come. It is therefore necessary to discuss what is meant by 'human flourishing', in order to make decisions that are directed towards this aim. Furthermore, a critical examination of the normative philosophical theories such as consequentialism, deontology and virtue ethics is necessary to uncover their ability to meet the ethical challenges and move towards these ideas of 'human flourishing'.

There are two main sections to this project. The first section outlines the problem. I will explain CRISPR technology and list some of its potential applications in humans. I will outline the ethical challenges of gene editing that this technology has brought to urgency and why it is unique. I will summarise the global response to gene editing and compare it to Aotearoa New Zealand's current response, discussing its ability to robustly meet these unique moral and ethical challenges presented by CRISPR.

The second section proposes a framework to address these issues. I will outline virtue ethics as a normative theory and critically evaluate its ability to meet the ethical complexities of gene editing, in comparison to consequentialist or deontic theories, showing why developing a network of virtues to guide decision-makers on gene editing policy is a viable option. I will outline my own set of virtues I see as essential to this task in Aotearoa New Zealand. In response to a common critique of virtue ethics, being a lack of specific action guidance, I propose a combination of casuistry methods in conjunction with the virtues to provide support and structure to a values based approach. To demonstrate my theory, I will discuss how the combined theories of virtue ethics and casuistry can inform ethical decisions within specific cases.

This research presents recommendations framed in a way that could inform decision-makers on the ethical approaches to gene editing both globally and in Aotearoa New Zealand. As the issues in this project are complex and multifaceted, this work cannot represent the definitive, final answer to specific cases. However, it will shed light on the complex ethical issues at play and uncover a gap in Aotearoa New Zealand's present policy response to gene editing practice. This project highlights the need for deeper, values based discussion around gene editing practices. In particular, I advocate for the inclusion of virtue ethics alongside standardly held approaches for further research in this kind of applied field.

Finally, using a case study, I will conduct a thorough analysis of how these issues can be seen in a more nuanced way using a combined philosophical framework of virtue ethics and casuistry. This work will show that these two normative theories work together as valuable tools that better position decision-makers in approaching the task of making ethical judgements in human gene editing applications through CRISPR.

Chapter 1: Introducing CRISPR-Cas9

This section introduces CRISPR-Cas9 as a breakthrough technological tool in gene editing. I will summarise how it was discovered and how it works in comparison to other gene editing technologies with a view to explaining why CRISPR-Cas9 has been touted as a game-changer for gene editing into the future and thus, for ethics too. Using examples of its current and proposed applications in humans, I will introduce some of the potential promises and pitfalls for its widespread use.

1.1 What is CRISPR-Cas9?

In 1987, researchers observed a pattern of short repeats of DNA sequences with non repetitive "spacers" between these sequences in the genome of E. Coli bacteria (Ishino, Krupovic and Forterre, 2018). These were named CRISPR (Clustered regularly interspaced short palindromic repeats). It wasn't until 2007 that the function of CRISPR in nature was discovered. CRISPR acts as a sort of homing device that guides a particular enzyme (Cas9) to a specific section of a DNA sequence. The Cas9 enzyme acts like a pair of molecular scissors to cut a strand of DNA, interrupting its sequence. Together, CRISPR and Cas9 work to modify the genes in a cell by disabling or repairing genes in the places where Cas9 has made the cuts. When observed in E. coli, CRISPR-Cas 9 allowed the bacteria to record segments of viral DNA they came into contact with in their own genome. The genome of a virus contains the genetic material necessary for the virus to continue replicating. When that virus re-attacked, the bacteria could recognize the DNA sequence within the genome and cut out viral strands of DNA, preventing the virus from replicating and destroying the bacterial cell. The CRISPR function, therefore, is a vital component of the bacterial immune system in the fight against viruses. Several years after this exciting discovery in nature, scientists began developing CRISPR-Cas9 as a simple yet powerful tool for editing genomes across a variety of organisms (Caplan, et.al, 2015).

1.2 How Does CRISPR-Cas9 Work?

On each strand of DNA is a series of coded sequences that collectively make up the genome of an organism. Specific codes (genotypes) inform the genetic expression or characteristic traits of an organism (phenotype) (Caplan, et.al, 2015).

The process of CRISPR-Cas9 was first observed in bacteria over three main stages (see figure 1 below): First, in the *adaptation* phase, viral DNA is cut into short segments to be inserted into the CRISPR sequence. This changes the original DNA sequence. Second, in the *processing* stage, the CRISPR repeats are copied from DNA to a RNA (Ribonucleic acid) chain, each carrying a part of the next repeat sequence. This RNA chain is cut into short pieces called CRISPR RNAs. This RNA then guides molecular material to the DNA target. Once it reaches its target, it can turn off, knock out or change the sequence of the gene in the *interference* stage. This is akin to deleting or editing words when writing a document.

There is a built-in safety mechanism, which ensures that Cas9 doesn't just cut anywhere in a genome. Short DNA sequences known as PAMs (Protospacer Adjacent Motifs) serve as tags and are positioned alongside the target DNA sequence. If the Cas9 complex doesn't detect a PAM, it won't cut (Alkhnbashi, et.al, 2014).

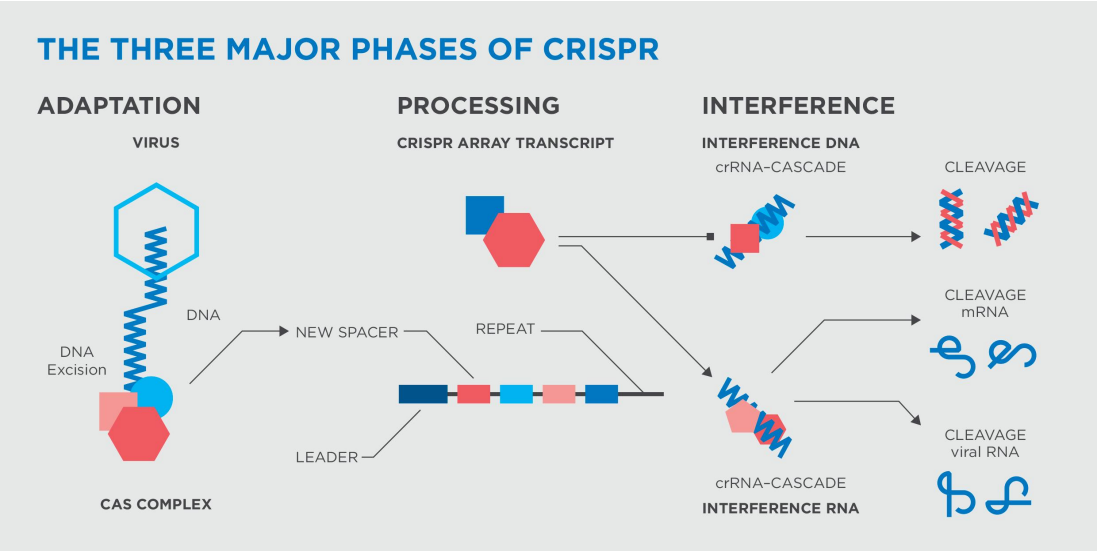

Figure 1: The Three Major Phases of CRISPR

The specificity of The CRISPR-Cas9 immunity system to recognise and destroy viruses that would attack a bacterial cell is not just useful for bacteria. Instead of relying on bacteria to produce CRISPR RNAs, scientists are now able to design and synthesize RNA molecules to match a particular DNA sequence so they can direct this process artificially.

In 2012, researchers were able to reprogram Cas9 to target specific genetic sites by creating a single synthetic guide for making cuts to specific sites on a genome. This made CRISPR into a simple tool for use in the lab (Jinek et.al, 2012).

In 2013, Feng Zhang was the first scientist to successfully adapt CRISPR-Cas9 for genome editing in eukaryotic cells, the kinds of cells present in humans, which have a nucleus that is enclosed within membranes, (Cong et al., 2013). This research was done using eukaryotic cells of humans and mice. Their study also showed that CRISPR could be programmed to target multiple locations on the genome (Cong et al., 2013).

Creative applications of this CRISPR defense system are now being applied in a variety of fields including agriculture, food production, research and medicine (Mulvihill, et.al., 2017). Although gene editing is not necessarily a brand new idea in itself, it is worth exploring how CRISPR may be different to some previously developed gene editing methods. The next section will briefly examine the two main ways in which gene editing can be done and then give a short comparison of these methods with the CRISPR system.

1.3 Types of Gene Editing

Gene editing can be done in two ways, affecting the organism differently. One way is somatic, meaning the changes affect the organism only and not any subsequent generations. Through this process, cells are removed, edited, and reinstated into the organism. This method could be used effectively for editing genes within a person to treat diseases such as sickle cell anemia and some cancers (Ormond, et.al, 2017).

The second way gene editing is done is through germline editing. This is where changes are made in the reproductive cells of a person. These changes will therefore affect future generations. This method offers hope for the eradication of serious heritable diseases within an individual and for all their descendants. Germline editing is currently not fully developed for widespread use in humans just yet but it is imminent (Ormond, et.al., 2017).

Somatic gene editing is somewhat less controversial, because its effects are confined to the individual. However it does carry its own set of ethical dilemmas when determining which attributes of a person are ‘disorders’ to be treated or merely

'enhancements' of an otherwise healthy individual. The issue of somatic enhancement eugenics is significant. Germline editing is however a more significant and therefore more contentious ethical matter due to the lasting effects on generations to come. These issues will be expanded upon in the following chapter.

1.4 Gene Editing Methods: A Brief Comparison of ZFN, TALEN and CRISPR-Cas9

To date, there are three main techniques that have been developed for genome editing based on synthetic nucleases and transcription factors, namely, zinc finger nuclease (ZFN), transcription activator-like effector nuclease (TALEN), and CRISPR, (Gaj, Gersbach & Barbas, 2013).

ZFN and TALEN consist of programmable, sequence-specific DNA-binding modules that enable a broad range of modifications to be introduced using a process of double DNA strand breaks that trigger repairs to genomes at specific locations.

ZFN are artificially engineered chains of zinc proteins with an enzyme called FOK1 attached to the end of that chain. ZFN recognise and bind to specific triplets of DNA code sequences. The FOK1 enzyme is derived from bacteria and acts as an endonuclease, meaning it cuts the DNA at certain recognised sequences. When the ZFN is positioned on both strands of the DNA, the FOK1 molecules form a dimer, a chemical compound made of two smaller identical or similar molecules (monomers) that are linked together. This dimer formation activates the enzyme and the section of DNA is cut, creating a double strand break. The places where these double strand breaks occur on the DNA strands is where editing of the genome can occur, either by cutting out sections altogether or introducing new sequences. However, difficulties in synthesising the ZFN commercially makes it expensive for large scale use (Gaj, Gersbach & Barbas, 2013).

TALEN was discovered in bacteria that infect some plants. Much like the protein chains in ZFNs, this involves FOK1 attached to the end of protein chains, this time called TAL effectors. The TAL Effectors bind to DNA in a similar way to ZFN's, however the TAL Effectors bind to individual nucleotides in a DNA sequence rather than triplets. The partner molecules bind to the other strand and the attached FOK1 enzymes cut the strands, creating a double strand break across the DNA. By recognising and binding to single nucleotides rather than triplets, the interactions between TALEN-derived DNA binding domains and their targets are less complex

and more user friendly than ZFN. However, the major challenge for TALEN is to clone the large modules in a series and join these modules in a designed order efficiently (Gaj, et.al, 2013).

1.5 How Does CRISPR Compare?

The CRISPR-Cas system offers several advantages over the ZFN and TALEN systems. Most importantly, CRISPR technology is very simple, easy to use and cheap in comparison. Previously, the tools used in gene editing were expensive and imperfect, so repeated trials were difficult to carry out. With CRISPR, scientists are able to harness and control a naturally occurring process. What would cost many thousands of dollars by other methods can be done for only a few hundred dollars (Cui, Xu, Cheng, Liao & Peng, 2018). This has allowed scientists to carry out multiple experiments at low cost.

However, as advantageous as the technology is, it has its own challenges. Theoretically, the CRISPR-Cas system is highly specific. When applied practically however, it is not immune to 'off-target' effects. These are random mutations that can influence other areas of the genome. Off-target effects can be mitigated by using Cas9 nickase, a modified version of Cas9 which creates a smaller nick in just one DNA strand as opposed to a double strand break (Zhang, Tee, Wang, Huang & Yang, 2015). The presence of these off target effects however means that total confidence in the effectiveness of CRISPR is not currently possible, so results need to be carefully and critically evaluated and tested.

Despite these difficulties, ZNFs, TALENs and especially the CRISPR-Cas systems are powerful tools for manipulating genomes. It is likely the refinements of these systems will continue and that they will be adapted in new ways. Experimental therapies that use ZFNs and TALENs continue to advance (Mullin, 2019). In the short term, there remain safety concerns around CRISPR, in particular with regard to off target effects. Older gene editing platforms are still being used until these concerns are allayed, but their fate remains to be seen.

1.6 Uses for CRISPR

Scientists have learned how to harness CRISPR technology for use beyond applications that involve bacterial immune defenses. It is now possible to make

precise changes in the genes of plants, animals and humans. If a particular genomic sequence on a strand of DNA is to produce a phenotypic expression that is harmful or undesirable, then CRISPR can be used as a tool to edit this sequence out of the DNA chain or insert new gene sequences altogether (Caplan, et.al, 2015). Because genes are defined by their specific sequences, they provide instructions on how to produce and maintain cells. Any change occurring in the sequence of even one gene can have a dramatic impact on the biology of the cell and the overall functioning of the organism.

The low cost and relative ease of use of CRISPR in gene editing particularly has opened up numerous possibilities for the future of life as we know it. Some major breakthroughs are already being discovered and developed through this simple yet powerful system. Currently, there are step by step instructions available online for anyone starting out with gene editing experiments of their own (Synthego, 2020). Furthermore, for around USD$180, a person can purchase a CRISPR starter kit and begin conducting experiments with editing bacteria at home (The Odin, 2020). This shows how CRISPR has broken barriers of cost and ease of use to become a tool in the hands of people outside of the laboratory setting, therefore expediting discussions around ethical regulation.

In this thesis, I will focus on the uses of CRISPR in humans, discussing the benefits and risks in terms of treatment of disease and enhancement of genetic expression in individuals. However, I briefly acknowledge that CRISPR will have wide reaching uses and effects outside of humans. Within the food and agriculture industry, there are experiments being conducted using CRISPR to engineer livestock that carry greater muscle mass for increased meat production and for modified crops resistant to disease, pests and a changing climate (Royal Society of New Zealand, 2020). CRISPR even allows for the manipulation of organisms to suit consumer preference. For example, flowers producing a wider variety of colours, or food with enhanced or modified flavors that appeal to consumers are all possibilities being explored through CRISPR. It is true that for thousands of years, humans have engaged in gene selection, through the careful breeding of certain crops and animals to eventually produce a form of controlled varieties. However, the process that once took many years can now be done within a single generation of an organism's life and carry a lasting effect (Royal Society of New Zealand, 2020).

1.6.1 CRISPR In The Lab

For laboratory research purposes, CRISPR has become an important tool in creating animal models with specific genetic changes and observing the progress and treatment of certain human diseases within these animals. For example, a study by Buchthal, Lunshof, Esvelt, Evans & Telford (2018) used CRISPR to genetically modify mice in order to develop immunity to tick borne diseases such as Lyme disease. Mice are known to be prolific carriers of ticks, so making them immune to the effects of tick bites is bringing hope towards a breakthrough in developing a similar immune response in humans.

A further study by Kyrou, et.al (2018) used CRISPR to suppress the population of a certain species of mosquitoes that carry malaria, thereby limiting the spread of the disease to humans. Their research showed that they could use a 'gene drive' to suppress a certain gene in these mosquitoes in Sub-Saharan Africa. A gene drive is a genetic system that gives certain genes vastly increased probability to be reproduced as a dominant expression throughout multiple generations. For example, during natural gene selection in sexual reproduction, offspring inherit two versions of every gene, one from each parent. Each parent carries two versions of the gene as well, so a particular variant of any gene that is passed on is determined by chance. However, 'gene drives' subvert this random allocation to ensure that the genetic modification will almost always be passed on, allowing that variant to spread rapidly through a population (Kyrou et. al., 2018). The gene drive in this case prohibited the female of the species from biting or laying eggs. When developed in this species of mosquitoes, after eight generations there were no unmodified mosquitoes left to reproduce and the population was extinguished.

1.6.2 In Medicine

CRISPR can be used for treatment of infectious diseases resistant to many forms of common antibiotic medicines. Widespread prescriptions of antibiotics have led to a rising prevalence of antibiotic resistance in humans and contribute to the current health crisis associated with the subsequent rise in drug resistant bacteria. Multiple copies of DNA carrying antibiotic-resistant genes can exist in each cell and can transfer antibiotic resistance between bacteria, inhibiting the ability to successfully treat a bacterial infection. Threats from antibiotic resistance could drastically increase drug-resistant disease deaths (Valderrama, Kulkarni, Nizet, & Bier, 2019).

In their study working with E. coli bacteria, Valderrama (et.al., 2019), developed a method (called Pro-AG), to disrupt the function of a bacterial gene that causes antibiotic resistance. Pro-AG effectively scrubs away the feature of the gene that passes on drug resistance.

Furthermore, there has been increased attention to how CRISPR can be used in the treatment of genetic diseases. In June 2017, a major breakthrough was discovered in the potential treatment of Huntington's disease, a fatal genetic disorder that causes degenerative nerve damage to the brain. The study showed that the disease was reversed in lab mice that had been engineered through CRISPR to have a human mutant Huntingting gene in place of a mouse Huntingting gene (Yang, Yang, Huang, Tang, & Guo, 2017). Researchers were able to snip out the part of the mutated gene known to produce the devastating expression of Huntington's disease.

In fact, CRISPR has already been trialled in humans. Researchers are using CRISPR as a technique for treating people with cancer (Salas-Mckee, et.al, 2019). The goal is to use CRISPR to assist a person's own immune system to attack cancer cells. The approach is similar to another more commonly used therapy called CAR T cell therapy, which engineers patients' own immune cells to fight their cancer, but with some key differences. As in CAR T, researchers collect a patient's T cells through a blood draw. T cells are cells produced in the bone marrow and are instrumental in the body's immune response to disease, including viral infections and cancers. However, instead of arming these cells with a receptor to assist in the attack against cancer cells, the researchers use CRISPR editing to remove three genes. The first two edits remove a T cell's natural receptors to make sure the immune cells bind to the right part of the cancer cells. The third edit removes PD-1, which is a natural checkpoint that sometimes prevents T cells from responding to the threat. Then, an affinity-enhanced T cell receptor is inserted which gives the edited T-cells a message to target a specific antigen, binding it to the cancer cells to destroy them. Results show that the edited T-cells bound to the cancer targets with no apparent serious side effects. These early results indicate that the procedure may be safe and feasible for wider use.

Founder and chairman of Parker Institute for Cancer Immunotherapy (PICI), Sean Parker stated,

> "Our purpose is to make sure [...] investigators have the support they need to bring bold ideas like this to life. These early findings are the first step as we

> determine if this new, breakthrough technology can help rewrite how we treat patients with cancer and perhaps other deadly diseases. CRISPR editing could be the next generation of T cell therapy, and we are proud to be a part of the first human trial in the United States." (Penn Medicine News, 2019)

However, small sample sizes and the scope of the experiments show that there is much more research to be done to determine whether using CRISPR is truly a safe approach on a broader scale.

1.6.3 Challenges Ahead

These are just a few examples of the myriad of ways CRISPR is being used. The simplicity of CRISPR opens possibilities for gene editing for a large variety of purposes and across multiple industries and scientific fields. Whether it's in the treatment of disease in humans or addressing food shortages, what is clear is the level of excitement around future possibilities for human life and across multiple industries. However, this brings forth the question of how we can ensure that these "bold ideas" can be pursued while ensuring the safety and ethical integrity of widespread CRISPR use.

It is clear that since the advent of CRISPR, there is renewed vigor for developing the tremendous potential of gene editing for producing life saving treatments. However, the pace at which such technology is developing is outstripping the pace of regulatory policies on gene editing. Without adequate policy concerning the ethical issues of such practices, there are potentially harmful consequences for humanity, including the spectre of eugenics and all of the issues this raises.

Chapter 2 - Ethical Challenges

In this chapter, I will outline some of the ethical challenges that are tied to the application of gene editing technologies generally. Beginning with a discussion of a common underlying philosophical debate at play within bioethics, I will go on to explore some of the unique challenges that CRISPR presents. Finally, I will explore some of the global responses to handling these challenges and investigate Aotearoa New Zealand's current position on gene editing applications.

The ethical issues surrounding gene editing, particularly germline editing are not new. There has been an ongoing debate about how we should use gene therapy, especially in humans, if at all. Much of this is due to the ongoing difficulty amongst the scientific, governmental and even religious communities to definitively clarify the line between treating human ailments and enhancing human life for non-medical reasons. However, a more fundamental question goes deeper than that. The emergence of such user-friendly gene editing technology in CRISPR runs us directly up against our previously held notions of what it means to be a human and have a flourishing, healthy life. In a few short decades, researchers have moved away from money and labour intensive experiments in the lab, to relatively cheap, fast gene editing. Human genetics was previously considered a matter of pure chance, with nature firmly in the driver's seat regarding how we appear and exist on this planet. The power to determine human genetic makeup has now shifted closer to being within our control. With such newfound dominion over our DNA code, it is imperative we ask these fundamental questions around human flourishing to ensure that we use it ethically.

To understand the more practical issues surrounding gene editing, it is necessary to look at the underlying belief systems that inform debate and decisions on gene editing. One of the ways to approach the issue of human enhancement involves two opposing philosophical approaches: Transhumanism and Bioconservatism. What follows is a brief summary of the transhumanist and bioconservatism positions.

2.1 Transhumanism and Bioconservatism

Transhumanism is the belief that the human race can, and should evolve beyond its current physical and mental limitations. The goal of improving and advancing the human condition is thought to be brought about through the development and use of

technology (Hayes, 2018). Sir Julian Huxley is regarded as a figurehead for transhumanism, arguing that humans are not only able, but compelled to transcend their own human nature and therefore realise new possibilities for the human race (Huxley, 1968, p.76).

> "It is as if man had been suddenly appointed managing director of the biggest business of all, the business of evolution, appointed without being asked if he wanted it, and without proper warning and preparation. What is more, he can't refuse the job. Whether he wants to or not, whether he is conscious of what he is doing or not, he is in point of fact determining the future direction of evolution on this earth. That is his inescapable destiny, and the sooner he realizes it and starts believing in it, the better for all concerned. What the job really boils down to is this the fullest realization of man's possibilities, whether by the individual, by the community, or by the species in its processional adventure along the corridors of time." (Huxley, 1968, p.73)

Transhumanism began to gain traction amongst intellectual circles in the 1980's. The movement became more official with philosophers Nick Bostrom and David Pearce establishing the World Transhumanist Association (WTA), an international non-governmental organization working toward the recognition of transhumanism as a legitimate subject of scientific inquiry and public policy (Hayes, 2018).

It follows then that the Transhumanist is very much in favour of the use of gene editing for both medical treatment and enhancement (Vallor, 2016, ch.10). The transhumanist holds that decisions about what is a genuine 'enhancement' should be left to private individuals rather than controlled by government or committees. This argument is based on the claim that most individuals who wish to use gene editing techniques will have good reasons to choose enhancement for themselves and their children (Bostrom, 2005). This is an assertion of the idea that people would know what is best for themselves, having thought carefully and clearly about such issues so as not to perform genetic edits for frivolous reasons. The transhumanist rejects the idea of a unified sense of flourishing and holds that humans will splinter and expand into multiple versions of flourishing in the achievement of some, currently unspecified end (Vallor, 2016, ch.10).

Vallor (2016) argues that the problem that transhumanists face is that despite a passionate call for transcending the present human condition, there remains a lack

of clarity on why transcending the human condition is preferable or necessary. There seems to be no specific end goal, or indeed a knowledge of what exactly humans are to wish for. After all, embracing technology freely with the aim of transcending our human condition may not actually be conducive to human flourishing. Not all growth and change is equal to flourishing; some change is destructive. Transcending our humanity does not automatically equate with human improvement.

Conversely, bioconservatism in the human enhancement debate endorses the conservative claim that we should reject the use of biotechnologies that enhance natural human capacities, such as gene editing or artificial intelligence technologies integrated with the human organism (Roache & Savulescu, 2016, ch.10). Bioconservatives range in political perspective from right-leaning religious and cultural conservatives to left-leaning environmentalists and technology critics. What unifies bioconservatives is a deep skepticism about medical and other biotechnological alterations of the natural world (Roache & Savulescu, 2016, ch.10). Michael Sandel, an outspoken critic of gene editing argues strongly for a bioconservatism stance by employing virtues such as humility, solidarity and responsibility in defending his position against gene editing (Sandel, 2004). To the bioconservatist, human enhancement technologies are thought to be 'dehumanizing'. The worry is that these technologies might somehow undermine our human dignity or inadvertently erode something that is deeply valuable about being human (Bostrom, 2005).

This concern of biotechnology leading to 'dehumanization' is difficult to factor into a quantifiable, cost-benefit analysis. It is possible to offer a vast number of modifications to the human body, both for medical and aesthetic reasons, to which most bioconservatism would offer little or no objection. Consider organ transplants, or routine surgeries to remove or implant devices (such as pacemakers) to manage or cure disease. It is tricky to definitively pinpoint exactly what aspect of transhumanism presents a moral stumbling block sufficient to justify the bioconservatist position. If the aim of the bioconservative is to preserve human dignity, there are many areas where technology can be strongly argued to do just that and indeed improve quality of life. If, for example, the bioconservatist is in favour of the use of a pacemaker but against genetically removing the need for them, this becomes a difficult position to justify. Without proper justification of what exactly is dehumanizing about gene editing or other enhancement technologies then for bioconservatism, this represents a challenge.

Furthermore, some enhancements arguably do preserve human wellbeing. For instance, perhaps we may develop technology that could enhance the natural senses of those who are in positions of protection or national security so they can detect danger more quickly and prevent large scale attacks. If this was done by some other means such as a removable device worn on the body or even an implant, the bioconservatism may not have an argument against this.

It seems that somewhere between these two stances lies the correct view. The question we should be concerned about is where the compromise between these extremes lies. It is my argument that a principled, yet flexible approach is required to navigate this issue, one that can accommodate for the value-laden nature of such broad, philosophical debates across an increasingly ambiguous moral landscape in light of the rapid pace of technological development. I will now move to outline a few of the significant, immediate ethical issues that have arisen over the last few decades regarding gene editing more generally.

2.1.1 Technology

The first area of concern pertains to the power and limitations of the technology itself as it is today, such as 'off-target' mutations and incomplete editing or mosaicism (Wang & Wang, 2019). Off-target mutations refer to unintended genetic modifications that can arise through the use of gene editing. Genetic mosaicism refers to an incomplete edit or modification of an organism, leading to the organism having multiple sets of cells with different genotypes.

Even once a gene has been successfully edited, there remains an incomplete understanding of how it will interact with other genes and in phenotypic expression. It may be possible to improve the accuracy for editing in a single gene, however, many phenotypes involve multiple genes interacting in a number of complex ways. Environmental factors also influence phenotypes, so researchers may be more unsure about results in subjects once outside of the laboratory. To presume that editing a specific gene will change a desired phenotype is to claim a full understanding of all the interactions involved in the genetics of that case. This understanding is far from complete. Although the risks and benefits of many such therapies are increasingly better understood, questions regarding safety and efficacy remain.

2.1.2 Disease or Not?

Early suggestions that CRISPR could be instrumental in eradicating previously untreatable diseases lends to the thought that this technology will be of immense benefit to humanity. There are cases where intervention through gene editing would clearly be beneficial, for example in the treatment of Huntington's disease or some cancers. With a better understanding of gene editing techniques, less controversial applications involving somatic gene editing for therapeutic purposes have significant public support globally (Chritchley, et al., 2019). These applications include for example, "editing the blood stem cells of patients who have a congenital blood disease, metabolic disorder or immune deficiency, or improving the capacity of immune cells to attack cancer cells." (KNAW, 2016, p.2). Somatic gene editing applications could therefore aid in developing treatment for genetic diseases such as Sickle-Cell disease, Hemophilia B, Cystic Fibrosis, neurodegenerative diseases, some cancers and viral infections like HIV (NASEM, 2017).

In that case, we might think that one easy rule is: it is permissible to treat diagnosed diseases. However, once we push further, past these apparently morally 'easy' cases, the ethical lines very quickly begin to blur. We run into questions of what counts as a disease and what counts more as a *way of being* human in the world. In February 2017, a multidisciplinary committee of the National Academies of Sciences, Engineering, and Medicine published a comprehensive report on the use of gene editing applications in humans. The Committee was in favour of somatic gene editing for treatment of disease but did not make any provisions in favour of enhancement, stating, "transparent and inclusive public policy debates should precede any consideration of whether to authorize clinical trials of somatic cell genome editing for indications that go beyond treatment or prevention of disease or disability" (NASEM, 2017, p. 110).

It isn't always clear when we move from talking about eradicating disease to talking about the 'correct' way to be a human being. If people had the ability to edit the human genome only a few generations ago, arguably there are some kinds of people that may have been eradicated whom we now see as perfectly good ways to be human in the world. Perhaps even making allowances for germline editing for medical purposes raises the spectre of eugenics. How we as a society choose which human features are pathologized and which are simply part of a diverse population

will depend on our personal and collective values. It is worth acknowledging at this point, that such a claim is controversial, as some philosophers deny that values are an important consideration for attribution of disease (Boorse, 1975). However, even such commentators will admit that determining which diseases are treated and which are not does involve values. Boorse states that even to label something as a 'disease' is to place a value of condemnation on such a state (Boorse, 1975, p.50). Values can vary significantly between cultures, within a culture, across time (especially pertinent for germline editing) and regarding a wide range of human features. If we are able to actually begin changing the DNA of our species according to what we value as more or less desirable characteristics, it may signal a precarious future for those who are not considered a desirable fit.

The distinction between what makes something a disease or an alternative way of being human is sometimes complex. For example, editing out Huntington's disease might seem an easily acceptable use for gene editing, but considering eradicating something like Trisomy 21 (Downs Syndrome) is much less clear cut. Deciding which aspects of humanity are acceptable or useful in society carries a heavy burden of value.

Second, there are issues around what is acceptable in terms of curing disease as opposed to human enhancement. If enhancing intelligence for some and not others causes moral discomfort, it is important to think about why. The issue with enhancing someone's intelligence may create an unfair advantage to some over others. Perhaps enhancing someone's intelligence would somehow alter a person's fundamental identity. Now, consider a case of ADHD (Attention Deficit Hyperactivity Disorder). If someone was diagnosed with ADHD, currently classified as a disorder, then surely there is a responsibility to 'cure' it if it became possible to do this through CRISPR. However, in this case, the claim is that people should not have short concentration spans (a way of being in the world). If there is doubt over this claim, or even if it is completely wrong, then it is not 'curing' ADHD, but 'enhancing' humans to adopt a particular way of being in the world. In this way, ADHD touches on both issues. First, there is the suggestion that people who have trouble maintaining focussed attention are not human in the 'correct way'. Second, there is a question over whether increasing ability to maintain focus is a 'cure' or an 'enhancement'.

So, even if we just make the distinction that it is acceptable to only deal with disease and not enhancements, it is imperative that we develop a well motivated framework of what characteristics we classify as disease and what are enhancements. We know that this is not always easy to deduce, which then presents a problem both for the distinction itself and for the eugenics problem. Historically, there are examples of terrible atrocities committed against humanity in the name of eugenics even without such powerful technology, such as involuntary sterilization of groups considered to be less acceptable in society (Koonz, 1992).

Current examples which are causing concern today include people living with Trisomy 21 (Down Syndrome), Achondroplasia (Dwarfism) or deafness. Some members of these communities have raised serious objections to some of the potential uses for gene editing. It is important to note that Trisomy 21 is chromosomal rather than due to a specific gene, so I acknowledge a slight disanalogy in the context of gene editing specifically. The example of Trisomy 21 however is an ongoing issue, and can be affected via selective termination following prenatal screening tests. In Iceland for example, where a comprehensive screening program is in place for expectant mothers, in 2004 and 2005 all fetuses identified with Trisomy 21 were aborted (Gottfreðsdóttir & Björnsdóttir, 2010). This example speaks to a precedent towards the eradication of certain lifeways. A study by Tafazoli, Behjati, Fatrhud and Abbaszadegan (2019) shows that CRISPR could be used to edit out certain genes that predispose those with Trisomy 21 to a higher risk of certain traits, such as intellectual difficulties. Regarding a proposed treatment for deafness, biologist Denis Rebrikov claims to be working with a deaf couple to genetically modify embryos in order to produce a child that does not carry genes for deafness (Cyranoski, 2019). Many members of such communities strongly oppose the idea that they are disordered or diseased and carry grave concerns about how gene editing and gene selection could narrow population diversity and eradicate certain groups altogether (Mozersky, et al., 2017).

There are further ethical considerations in the area of public health. It is unclear what, if any, interventions should be made in the interest of promoting the chance of healthier lifestyles, in the absence of any disease at all. For instance, if a gene-editing approach allowed for reduction in harmful cholesterol levels, promoting healthier individuals with decreased chance of developing heart disease, this could be considered an enhancement towards reducing the potential for negative and costly health outcomes, even the prevention of premature death. We

would need to examine if it would be right in performing such enhancements in the name of such benefits, even if it meant removing the potential person's possible desire not to have genetically modified or enhanced genes. This scenario exemplifies how increasingly contentious and difficult it is to determine whether cases like this should be classified as an 'enhancement', or a necessary medical intervention in the interest of public health.

There are two entangled issues here. The "disease issue" and the "right kind of people issue". There are decisions to be made regarding the kinds of people who will be represented in future generations, and the distinction between what is helping people with disease and what is enhancement according to an ideal version of being human.

2.1.3 Social Concerns

There are wider socio-political issues around how gene editing can contribute to inequality in terms of fair access to any decision-making processes or potential benefits of the technology. An example of this is in the production of nutrient enhanced crops and livestock. In 2018, The World Health Organization estimated that 821 million or 1 in 9 people worldwide were undernourished and approximately 2 billion people were unable to obtain key nutrients like iron and Vitamin A (World Health Organisation, 2018). If, through gene editing, people could fortify or improve nutrient content in foods then decreasing malnutrition and increasing access to higher quality foods is possible (Hebert, 2018, p. 510). If political relations are strained between countries who have access to this technology and those who do not, this could lead to increased power imbalances globally.

Returning to the issue of human enhancement however, there is moral weight in considering if this technology will be 'equal access' or instead used, even unintentionally, as a catalyst for increased global inequality. Globally, people are not equally situated with regard to the benefits and harms of biomedicine and biotechnology. Certain groups, or nations may be disproportionately affected through the development of - and therefore the access to - benefits or decision-making processes regarding gene editing technologies (Nuffield Council on Bioethics, 2016, p. 29-30). Care needs to be taken to ensure that access to gene editing technologies does not exacerbate existing social inequality at a genetic level. Unfair distribution of such opportunities amongst various societal groups could

become entrenched across generations. For example, an initial financial or political advantage could be converted to a genetically enhanced population in terms of enhanced physicality or IQ. Should this become generationally entrenched, the social inequities that exist today could find new footing at a genetic level, creating a kind of genetic class system.

A study by Brineger et.al (2017), focuses on the increased interest from private companies in the commercialization of genome editing and patenting of certain genetic modifications and techniques. This introduces another set of complex ethical issues where genes become a commodity, possibly influencing socioeconomic divisions and wealth disparities. This brings the issue of access to the fore. If, for instance, research and development of the technology is government - and therefore taxpayer funded, it can be argued that it is morally wrong to limit access to potentially life saving benefits of such techniques to those who indirectly funded the development of the technique. While this problem is not unique to this particular situation, it may not be prudent to rely on a free market to provide equitable healthcare.

2.2 Why is CRISPR Unique?

All of the aforementioned issues are recognised concerns regarding gene editing. However, when these concerns arise regarding gene editing through CRISPR this makes them especially urgent. The emergence of CRISPR represents a new challenge. What makes CRISPR unique over other editing technologies is primarily due to the ease of use, accessibility and affordability of the technique. The development of CRISPR has therefore advanced the progress of gene editing at a rapid pace and it is now at the forefront of gene editing applications. CRISPR has brought the established ethical issues around gene editing into sharp relief, requiring urgent attention. The task of working through the uncomfortable relationship between ethics and science is of paramount importance. It is vital that the scientific and philosophical communities become accustomed to working collaboratively to manage the exciting and worrying aspects of CRISPR.

For gene editing through newer technologies such as CRISPR, a common concern amongst the literature is a lack of clear, unified systems to inform policy. Mulvihill et al., (2017, p.19), state that current ethical guidelines around genetic modification are not equipped to meet the ethical demands of gene editing through the CRISPR

method in particular. Whilst the article does not identify any new ethical issues of gene editing using CRISPR compared with existing gene therapy or genetic engineering technology generally speaking, it notes that the sheer speed of new findings using CRISPR does accelerate the need for further research into the management of such issues (Mulvihill, et al., 2017, p. 19). The article maintains a particular focus on the principle of solidarity in gene editing research practices as the pathway forward towards ensuring the public good (Mulvihill, et al., 2017, p. 24). It is notable that the philosophical approach in this article situates gene editing through CRISPR as a question of value or virtues, rather than weighing up the consequences that may eventuate from this technology.

Similarly, Caplan et.al, (2015) discuss an urgent need for effective, global regulations that govern the testing and environmental release of Genetically Modified Organisms (GMOs). The speed, low cost and ease of use of CRISPR motivates the need for robust regulations on gene editing in all organisms (Caplan, et al., 2015, p. 1421).

Crucially, the speed at which CRISPR is being developed and utilised makes it difficult to predict and stay ahead of the myriad of specific ethical dilemmas which may come to light. This is problematic when attempting to create robust regulations around its use. Regulations governing gene therapy research may facilitate the safe development and oversight of some clinical trials involving CRISPR based editing applications. However, where such ethical awareness and monitoring are lacking, safety and privacy risks are likely to increase. Cheaper and easier access may mean that applications become available within months of concept, rather than years. The standard processes of ethically vetting such procedures are therefore out of step with these possibilities because formulating new policies or making the changes required to existing policies will likely be too slow in coming when compared with the developmental pace of gene editing technology. This is a particular concern when considering the potential for CRISPR to be utilised outside of the controlled laboratory setting, with the availability of CRISPR kits for private sale online, as previously mentioned. In fact, there is a movement that campaigns for this specifically, opening up arguments around access.

2.2.1 The Politics of Access

One way to avoid CRISPR's ethical issues might be to demand that its development is slowed down and heavily restricted. However, this may not be the right thing to do, especially when considering the potential for treatment of disease. Some argue that because CRISPR is relatively easy, cheap and accessible, it should remain that way for the general public, rather than being captured and controlled by the government or private enterprises only. As this technology stems from a discovery in nature, there is an argument for the free and unfettered access to all who wish to use it. Former NASA biochemist Josiah Zayner is an outspoken advocate for such an approach. His CRISPR kits for sale online have caused a controversy amongst the scientific community and warnings from the United States Food and Drug Administration (FDA) that selling gene therapy products without their approval is illegal (Ireland, 2017).

Zayner has become a major figure in the "biohacker" movement, a collective of artists, designers, scientists and engineers who believe that gene therapy products such as CRISPR should remain in the public domain. His belief is that humans pursue ideals of autonomy and equality. It is these ideals that fundamentally drive a desire to control one's own genetic profile and expression. Zayner asserts that humans should be educated on how to use CRISPR for themselves and empowered to treat themselves with gene therapy as medicine. In a move demonstrating his beliefs, Zyane became the first person to inject himself with CRISPR modified DNA designed to increase muscle mass whilst being filmed during a talk he was giving on CRISPR uses and accessibility. In a 2017 interview with The Guardian, Zayner stated that treatment of disease or enhancement at a genetic level should be considered the ultimate medicine (Ireland, 2017). Whilst Zayner makes a valid point relating to the benefits of cheaper and easier access to CRISPR for medical treatment, it does highlight the difficulties of CRISPR being effective in the hands of people who may knowingly or even accidentally, through untrained, underregulated actions, usher in some of the more harmful effects of gene editing.

This example shows how CRISPR technology has rapidly become a contentious issue embedded in social, economic and political spheres. CRISPR therefore requires a well considered, robust, ethical response, both globally and locally.

2.3 The Need for a Philosophical Response

Philosopher Shannon Vallor asserts that there is a vital connection between developing technology and ethics. She argues that the relationship between the two need to be a point of focus in order to seek and secure human flourishing, "Ethics and technology are connected because technologies invite [...] specific patterns of thought, behaviour and valuing; they open up new possibilities for human action and foreclose or obscure others." (Vallor, 2016, p.3). Vallor further explains how technology has advanced so much in recent decades, that it has the ability to affect a far wider proportion of the population, including future generations. Therefore, a contemporary theory of ethics, one that holds to an account of a good life, that guides us on how to live well with emerging technologies is required (Vallor, 2016, p.6).

Through CRISPR, it is now easier and more affordable to achieve greater control over our own DNA, something that until now was only left to chance and accepted as immovable. We worked around our genetic code as best we could. Now, our DNA can be seen as a potential barrier, a genetic 'glass ceiling' to break through with a few simple techniques. This leads to the question of how we are to learn to live well with technology that allows us far more possibility for change than ever before.

2.4 Global Response to CRISPR:

Therapeutic applications of gene therapy through CRISPR are on the increase, as the delivery of the technology becomes safer and more accurate (Cheng & Tsai, 2018). Presently, anticipation is building around such experimentation in The United States of America. In early 2018, for example, the US National Institutes of Health launched the Somatic Cell Genome Editing program. The program aims to improve the delivery mechanisms for targeting gene editing tools in patients, develop improved genome editors, implement safety testing of the genome editing tools in animal and human cells and create a genome editing toolkit containing the resulting insights for sharing within the scientific community (SCGE, 2018). Heritable genome editing, however, remains the CRISPR systems' most controversial application.

Since the advent of CRISPR applications, many professional, scientific and medical groups have formulated a response to the ethical challenges of CRISPR and how it should be used in gene editing, if at all. Most statements pertaining to the use of CRISPR concur that for the time being, heritable germline experimentation should be prohibited, although reports from the Netherlands, the United Kingdom, Spain, and the United States of America suggest that this could become permissible if a number of conditions can be satisfied. For example, The NASEM Committee's report specified a framework in which germline editing may be used:

> "The absence of reasonable alternatives; restriction to preventing a serious disease or condition; restriction to editing genes that have been convincingly demonstrated to cause or to strongly predispose to that disease or condition; restriction to converting such genes to versions that are prevalent in the population and are known to be associated with ordinary health with little or no evidence of adverse effects; the availability of credible preclinical and/or clinical data on risks and potential health benefits of the procedures; ongoing, rigorous oversight during clinical trials of the effects of the procedure on the health and safety of the research participants; comprehensive plans for longterm, multigenerational follow up that still respect personal autonomy; maximum transparency consistent with patient privacy; continued reassessment of both health and societal benefits and risks, with broad ongoing participation and input by the public; and reliable oversight mechanisms to prevent extension to uses other than preventing a serious disease or condition" (NASEM, 2017, p. 134-35)

This shows that serious misgivings remain regarding gene editing and there is room for further research and debate regarding the ethical challenges before even beginning to formulate robust policy around its use.

2.4.1 The Local Context

The broad range of potential applications of CRISPR could reignite ethical debates generated by earlier forms of genetic modification in Aotearoa New Zealand. Prior to CRISPR, early applications of gene editing technologies to create transgenic organisms stirred significant public concern, leading to the establishment of a Royal Commission of Inquiry into Genetic Modification in 2001. Based on over 10000 public submissions, the Commission developed its report which informed the

current stance that the growing of genetically modified crops is prohibited (Royal Commission on Genetic Modification, 2001). Subsequently, there has been a substantial push towards relaxing these rules on environmental and economic grounds (Morton, 2019). When considering gene editing for therapeutic and research purposes in humans, the Human Assisted Reproductive Act (2004) contains legislation pertaining to these practices.

Since the establishment of the Act, there has been no formal update of policy on gene technologies in Aotearoa New Zealand (Royal Society Te Aparangi, 2019). This is significant, given that CRISPR was developed for practical use in the laboratory in 2012. So, in spite of the significant difference between CRISPR and the technologies for which this policy was developed, there has been no formal response since its arrival. This shows that Aoteara New Zealand urgently needs to officially form a revised response around its policy on gene editing, taking CRISPR into account. It is imperative that Aotearoa New Zealand weighs in on this debate and forms an approach that is suited to our unique cultural perspective, whilst still staying abreast of global developments and trends in gene editing.

The Royal Society of New Zealand (RSNZ) Gene Editing Panel aims to engage the public in discussions and provide advice to the New Zealand Government on potential options for regulation (Royal Society of New Zealand, 2016; 2017). Gene editing is currently considered genetic modification, meaning non-human gene-edited organisms are classified as “new organisms” and are thus subject to approval processes under the Environmental Protection Authority, a process which includes the incorporation of Māori perspectives (Hudsen et.al, 2019).

In recent years, the RSNZ panel has considered the implications of technologies such as CRISPR, concluding that an overhaul of current regulations is due and that there is a need for nationwide discussion on how to proceed for the future. The panel discussed the use of gene editing in areas of healthcare, environment, pest management and primary industries. These discussions identified a number of potential issues, including that the legal framework is becoming increasingly out of date given the global advances in gene editing technology. Expert panel Co-chair Dr David Penman said that there is a need to move on from a black and white view of gene editing, towards a more nuanced view that recognises a wide range of applications of the technology, some of which may be more, or less acceptable to various communities than others. It is therefore important that Aotearoa New

Zealand forms its own views on the ethics of gene editing, given its unique cultural heritage and environment, including the unique challenges faced in maintaining biodiversity and a productive economy (Royal Society Te Aparangi, 2019) .

Because the focus of this project remains on ethical considerations for gene editing applications in humans, the following excerpts are from the panel's review of some of the key concerns as they pertain to use in this area. They describe the current values that underpin their recommendations.

On healthcare:

> "Gene editing of tissue to treat severe diseases controlled by a single gene is currently achievable and can be ethically acceptable if the treatment provides significant benefits to those for whom alternative therapies are limited, and if it has a reasonable prospect of being safe and effective, provided that patients are fully informed, and new treatments are subject to rigorous scientific and ethical review[....] For Māori whānau, that decision may align, or be in direct conflict with, Māori values and aspirations for flourishing whakapapa into the future. The benefits of the procedure should outweigh the risks, and there should be direct benefits for participants and their communities from a Te Ao Māori perspective." (Royal Society Te Aparangi, 2019, p.5-6)

On germline editing for medical purposes there is a clear concern for what we owe to future generations, from a moral perspective. The panel acknowledges the issue of having autonomy and ownership over one's body but recognises the tension between the desire to make decisions on behalf of those who cannot give consent, such as embryos.

> "This raises issues regarding 'intergenerational justice', or what we owe future generations [....] Where Māori embryos are concerned, it will be fundamental that culturally appropriate ethical processes that ensure the key values of whakapapa, tika, manaakitanga, and mana are upheld [...] It would be useful to consider the benefits of the procedure and whether those outweigh the risks. There should also be direct benefits for the participants and their communities." (Royal Society Te Aparangi, 2019, p.9)

On physical enhancement:

> "Whilst deleting particular genes can moderate disease properties, it is possible that similar, naturally-arising genomic events could confer desirable characteristics [...] without a medical purpose [...] In a Māori context, careful consideration should be given to the pūtake, the purpose of the procedure, and decisions taken in full consideration of culturally appropriate ethical processes that uphold the key values of whakapapa, tika, manaakitanga, and mana. Any benefits should outweigh the risks, and the outcome should benefit the Māori community." (Royal Society Te Aparangi, 2019, p.11)

The Panel highlights the need for a thorough evaluation of the purpose of any enhancements but does not necessarily rule them out as an option for the future. There remains however a strong cautionary tone in the recommendations grounded in having solid reasons for the enhancement, indicating a wariness towards a slippery slope of enhancement procedures that could become problematic in future. They have identified key ethical concerns around gene editing and in particular, have emphasised the need for an urgent review of current policy. They indicated a need for a principled approach based on values that situate us globally whilst being careful to reflect our specific cultural values.

> "The Panel would like to see a legal and regulatory system in New Zealand that is more future-proofed and 'fit-for-purpose' by being easier to navigate, having clear and consistent definitions, and providing a better basis for assessing the risks and opportunities of particular applications of gene editing" (Royal Society Te Aparangi, 2019).

This is a clear indication of the position of the Royal Society and what I aim to clarify and build upon throughout the rest of this project. The panel has made good progress in highlighting the need for a principled approach. However, there are some areas where these recommendations should be challenged on a fundamental basis to move to an effective implementation stage.

The recommendations uncover a number of issues. First, the move to say that gene editing is acceptable as long as it is safe and the benefits outweigh negative side effects is almost trivially true. The real work is to figure out how to assess these benefits and risks. Calculating any adverse side effects however remains difficult, particularly when attempting to carry out a risk assessment that extends

intergenerationally. Furthermore, there is debate surrounding whether we have a right to manipulate the genetics of future generations, and if so, the extent of our obligation to calculate the chance of doing harm to those generations that do not yet exist.

The second assertion that it should be accepted if it improves wellbeing, whilst not trivially true, it is close to it. There is no definitive, clear explanation of what "wellbeing" means. The panel does state that Māori perspectives and values should be upheld, but also states that sometimes the decisions made in gene editing will fly in the face of such values. Furthermore, the recommendations state that any editing applications in Māori embryos should benefit Māori communities, but do not make any suggestion as to what form these benefits could take.

Finally, the recommendations do not adequately distinguish between a cure and an enhancement towards wellbeing. The concepts of 'cure' and 'enhancement' relate to what we think a human life should be like and any decisions regarding gene editing applications will likely be dictated by values, which are inherently not objective. It appears that the panel is attempting to use a framework involving consequentialist calculations of utility alongside the recognition of certain cultural values, without adequately specifying how these approaches can be applied or how they might work together. Making decisions based on values and calculating utility are two distinctive approaches that have different aims. One concerns upholding a principle of living and the other concerns upholding maximum utility. Whilst it may be true that in certain circumstances, upholding certain values will lead to maximum utility, this is not always the case. Therefore, framing discussions combining these two methods will at least require substantial clarification. It is therefore not yet clear how incorporating this approach could be effective informing robust policy around gene editing.

In my view, the unique and rapid development of gene editing applications through CRISPR should move us to carefully consider the deeper ethical commitments and our values as a society to guide our thinking on the subject. A focus on predicting and calculating the risks and benefits is secondary to these deeper commitments. Creating policy based on a framework of these values and ethical commitments should form the basis of any practical measures on CRISPR use.

The panel has certainly highlighted the need for robust policy around the use of modern gene editing technologies like CRISPR. Questions remain as to whether there is a suitable ethical and philosophical framework that is capable of underpinning this work and can inform our approach to these ethical challenges that will shape biological life as we know it. Despite all the familiarity of a cost benefit framework, it may be time to rethink.

2.5 Next steps: A Philosophical Approach

The increased affordability and ease of access to fundamentally alter life as we know it through CRISPR, for generations to come, calls for an ethical approach that is robust, yet flexible enough to meet these rapidly developing challenges, both globally and in Aotearoa New Zealand.

Despite the clear and legitimate concerns, there is little doubt that CRISPR has become a valuable tool in research. Jennifer Doudner, a pioneer in the development of CRISPR has stated that her most pressing concern regarding the use of CRISPR centers around the misuse of the technology in such a way that it causes the general public to distrust and therefore disregard its incredible potential to help humanity in the fight against disease (Kuchler, 2020). Given the significant promise in terms of benefits and the potential for misuse, the global community must begin the work of revising outdated laws and recommendations, turning its hand to creating an ethically sound decision-making framework that is fit for dealing with the complex cases that CRISPR will likely bring.

The issue now centres around appropriate ethical management of developing technologies. It is necessary to discuss whether it is possible to create a set of fixed rules around gene editing or if a more flexible approach, one in keeping with the pace of technological change is required.

2.5.1 Ethics in Aotearoa New Zealand

In examining the RSNZ Panels response to gene editing, it is important to clarify whether utility calculations or rules are the dominant ethical framework or whether a combination of normative ethics frameworks are in play. Identifying the underlying theory is important so that there is a clear value system to rely on when particularly difficult cases arise. One particularly interesting feature in studying the excerpts from the Panel is that there is a view towards incorporating core principles of Tikanga but within a cost-benefit framework. 'Tikanga' can refer to the nature or function of something (Aotea Made, 2020). It isn't clear that a cost-benefit framework adequately accommodates the kind of nuanced and deep discussion required of applying principles of Tikanga because not everything that constitutes the nature of something can be understood in measurable terms that allow for a complete cost-benefit analysis. It may be the case that reimagining the kind of philosophical framework from which we approach these principles is more effective. Perhaps the kind of philosophical framework that holds principles of Tikanga and how these principles interact with one another at its core could better accommodate the kinds of challenges we face in applying CRISPR in humans.

Perrett and Paterson (1991), have discussed traditional New Zealand Māori ethics as being a values-based perspective. The authors show how Māori ethics is not centered on explicit rules for action but follows the ancestors, who are the model to the kinship group. And it is here that a key concept of Māori ethics, the concept of tika (naturalism), comes into play (Perrett & Patterson, 1991, p.187). In humans, this includes appearance, mannerisms, cultural practices and most importantly the inner character or life force that manifests itself through these expressions. The all-important quality here is that of being in accord with human nature, being "natural" and hence reasonable and correct. For Māori this means being in accordance with custom and common practice, for these are the form of human nature (p.187). A Māori view of the self is discussed as appropriately non-individualistic, identified more strongly within the collectivist thought and is narrative based (p.195). It is this radically non-individualistic conception of selfhood provided by collective traditions and interconnectedness with both other humans and the land which gives the context for which the individual may seek a life of flourishing (p.196).

Perret and Patterson's commentary on the values-based perspectives in Māori ethics as a means of seeking a life of flourishing has links with a Western tradition based on similar considerations connecting to the pursuit of a flourishing life : virtue ethics.

In the rest of this thesis, I will argue that such an approach is a serious contender for addressing the issues left open by the Royal Society's recommendations. This includes the need for a clear theoretical underpinning to strengthen the RSNZ response to CRISPR and what this theoretical framework might look like in practice on issues such as potential impacts on future generations and the treatment versus enhancement debate for a flourishing human life.

Chapter 3: Introducing Virtue Ethics

Virtue ethics is a normative theory that emphasizes the development of one's character as the source from which all right action is derived, rather than by the following of an external set of rules that are specifically action guiding. Virtue ethics is still concerned with what people do, however the focus is on the kind of people we ought to be. It rests on the assumption that if an individual possesses good moral character, then the right actions will naturally follow, without a prescriptive list of rules for action. For the virtue ethicist, the virtues themselves are held as the most important factor in morality and serve as the foundation of moral behaviour.

In Western philosophical traditions, Aristotle is considered the figurehead for classical virtue ethics. Aristotelian virtue ethics proposes that humans have a fixed nature, or the innate essence of a person. It is argued that the way we flourish is by adhering to that nature. This is what Aristotle describes as 'proper functioning' (Wenzel, 2010). Proper functioning holds that everything has a specific function and a moral agent is functioning well or poorly to the extent that they do or do not fulfil that function. For humans, proper functioning is concerned with the need to be healthy, grow and be fertile. Aristotle's account of virtue ethics asserts that humans are a 'rational' animal, and in this way, we need to function with reason and social skill in relating to one another (Wentzel, 2010). Adaptations of virtue ethics stemming from Aristotle have gained popularity within Western philosophical perspectives in recent decades, offering an alternative to more dominant normative theories such as deontology and consequentialism.

3.1 Eudaimonia

A core idea within Aristotelian virtue ethics is that developing a virtuous character serves the moral agent in living a holistically good and purposeful life, known as 'eudaimonia' (Wenzel, 2010). Eudaimonia includes the concept of happiness, although happiness is not the ultimate goal. A life of eudaimonia is rich and multifaceted. It includes a sense of purpose, the struggle of hard work or delayed pleasure in achieving overall contentment in one's body and mind and in one's relationship to the wider community. Eudaimonia acknowledges and allows for the endurance of short term discomfort for a long term gain. However, if a person is virtuous, their overall life will flourish and their actions will be ethical. Happiness or pleasure is the byproduct of purpose, rather than the goal. For the virtue ethicist, in

order to live a eudaimonic life, it is argued that one must be in possession of certain essential virtues.

3.1.1 Aristotle's Virtues

There is considerable debate around what exactly constitutes human flourishing and therefore also what virtues are essential for this. Aristotle identifies approximately eighteen virtues that he considered essential for a moral, flourishing life (Irwin, 1975). The virtues according to Aristotle stem from the concept of eudaimonia and are defined as habits of choice that are determined by reason (Simpson, 1992, p.507). Aristotle held the view that virtues are not considered to be fully developed from birth. Rather, they are developed through habituation, parental or other mentored guidance and training. Once adulthood is reached, then the training can serve to produce a virtuous person, whereas passions will dominate in a person who has not been trained in virtuous habits early in life.

Aristotle separated his list of virtues into two parts, those pertaining to emotion, called 'moral virtues' and those pertaining to intelligence 'intellectual virtues' (Pakaluk, 2005) (see Table 1 below).

Aristotle describes a virtue as being the golden mean between two vices or extremes, the vice of excess and the vice of deficiency (Wenzel, 2010). In some cases, this helps to clarify the meaning of the virtue itself. For example, the virtue of courage is the 'ideal' midpoint between the extremes of cowardice and recklessness. So, if someone witnesses a person being mugged in the street, they might immediately run to the aid of the victim and stop the mugging, putting themselves in harm's way to help the victim. This may seem like the right action to take, but it may also be reckless to do so without first assessing the situation and taking appropriate action. The properly courageous person would be able to discern the best course of action based on the specific circumstances. A reckless person may run head first into danger, while a coward may avoid the situation altogether in order to preserve their own life at any cost. If the robber appears to be physically stronger than the witness and therefore likely to overpower them, then courage may look like calling for assistance rather than directly confronting the robber. This example demonstrates how a virtue in different circumstances and involving different agents may produce varied actions and outcomes. In this way, virtue ethics allows for the adjustment of behaviour to fit varying circumstances in the world without betraying its core principle of virtue.

MORAL VIRTUES	INTELLECTUAL VIRTUES
Courage in the face of fear	Nous: Intelligence
Temperance in the face of pleasure and pain	Nous Episteme: Reasoning skills in applying scientific principles, formulas or tools
Liberality with wealth and possessions	Sophia: Theoretical wisdom
Magnificence with great wealth and possessions	Gnome: Common sense to make judgements and decisions
Magnanimity with great honours	Synesis: Understanding others' reasoning processes
Proper ambition with normal honors	Phronesis: Practical wisdom
Truthfulness with self-expression	Techne : Art, craftsmanship
Wittiness in conversation	
Friendliness in social conduct	
Modesty in the face of shame or shamelessness	
Righteous indignation in the face of injury	

Table 1: Aristotle's Virtues

3.2 Non Aristotelian Virtue Ethics Perspectives

Aristotle's list is not the only list of virtues, however. Despite many of his basic arguments maintaining relevance today, Aristotle's virtue ethics has been criticised for being elitist and exclusive in some accounts, with some fundamental and glaring flaws within Aristotle's worldview, such as his commentary on the role of women and slaves in society (Vallor, 2016). In light of these criticisms, Neo-Aristotelian ethics has emerged, retaining the relevant foundational arguments put forward by

Aristotle and adapting them to be more in keeping with contemporary worldviews (Statman, 2010).

Neo-Aristotelian virtue ethics has been linked to Anscombe's 1958 essay *'Modern Moral Philosophy'*. Anscombe asserted that until we have developed an adequate philosophy of psychology, which at the time she argued as being lacking, any concepts of moral obligation or duty should be set aside if at all possible. This is because she argued that they are derivative of one's character and that detaching moral duty from its foundation of virtuous character is harmful. Anscombe asserted that rules or duties toward action that are not first grounded in virtues will produce harmful and ultimately immoral practical outcomes (Anscombe, 1958, p.14).

Since Anscombe's work, there has been a resurgence of Neo-Aristotelian virtue ethics driven by philosophers such as Rosalind Hursthouse and Philippa Foot. Foot and Hursthouse in particular attach a naturalistic view to virtue ethics, stating that virtues are tied to our innate status as rational animals and distinguishing features of the human species (Hursthouse, 1999, p.167). Foot states that it is not considered unusual or difficult to make evaluative judgements about plants or animal species behaviour by referring to a general code of behaviour or features considered healthy or unhealthy, suggesting it is no great stretch to make such judgements of human nature in the same way (Foot, 1959).

Also, philosophical accounts of normative ethics that are rooted in virtues or similarly described characteristics for living a good life are documented historically, within and across cultures. This includes Confucianism, Buddhism, Christianity and arguably, embedded within the Māori worldview in Aotearoa New Zealand (Perret & Patterson, 1991).

Shannon Vallor discusses some aspects of Aristotle's theory as being based on wrong assumptions that fail to be relevant to wider cultural perspectives (Vallor, 2016). Accordingly, Vallor has written detailed comparisons between some Eastern and Western virtue ethics accounts in the development of her own account of virtues that she claims are vital to good moral living in the modern age of technology. Vallor discusses the need for incorporating a wider perspective of virtue ethics from Confucius, Buddhist, Christian and some more contemporary virtue oriented philosophies. Vallor states that since we have had the benefit of time to uncover these faults in Aristotle's philosophy, it stands to reason that we would see more

come to light as time goes by. In subsequent chapters I will discuss Vallor's approach, going on to develop a set of virtues pertaining specifically to gene editing decisions for Aotearoa New Zealand.

3.3 A Common Criticism of Virtue Ethics

The most common criticism levelled against virtue ethics is that it is insufficiently action guiding (Zyl, 2009). It is argued that the Virtues themselves as concepts, such as 'courage' or 'empathy' are too abstract for adequate practical application in real world dilemmas. This is because they are subjective and thus difficult to specifically quantify and measure. Asking a person to be courageous may be more difficult to interpret in action than asking a person to perform a specific act that represents courage. Unpacking the meaning of character traits as concepts in and of themselves takes a series of explanatory steps, whereas a prescriptive guide to action can be considered less complex to understand and execute consistently. This apparent lack of clear action guidance is said to render virtue ethics ineffective in giving a clear and decisive list of actions to take when faced with a morally ambiguous choice.

This criticism rests on some assumptions. First, that a good moral theory must be able to tell us explicitly what to do. Second, that a character-based moral philosophy cannot tell us what specific actions to take and furthermore, that a code of conduct, based on an analysis of duty such as deontology, or a consequentialist utility calculation, is simple and thorough enough that anyone, regardless of their character, could do the right thing by following it. Deontic and consequentialist theories do not regard the role of character as important, but rather the external, measurable actions that a person takes to uphold the moral maxim or utility calculation.

In response, the virtue ethicist can acknowledge that it is difficult to know which factors are generally most important to consider in making moral decisions. However, when considering the unprecedented ethical challenges ushered in with CRISPR applications, the flexibility of a theory that relies on virtues rather than external rules is arguably more compatible with such an unpredictable and complex external world. Two people of virtuous character could therefore approach the same morally challenging situation, respond differently to the event and have both actions be considered morally right (Statman, 1997, ch.1). Character based morality allows for multiple right responses to ambiguous situations. To the virtue ethicist, because

a correct action requires the ability to possess good judgment in order to make a decision, the focus should be on wisdom as a virtue rather than behavioural rule. Furthermore, a virtue ethicist can assert that it is not necessary to specify external rules around actions because if one is to be virtuous they are already in possession of good judgement and would know what is the right and wrong action at any given time without explicit rules on actions.

The following section will critically discuss whether this approach is robust enough to tackle the human complexities involved in applying gene editing technologies. I will further investigate some key criticisms of virtue ethics from proponents of consequentialism and deontology, explaining why virtue ethics may be an effective tool in facing the unique ethical challenges of gene editing and why deontology and consequentialism are not up to the task in this instance, at least not on their own.

3.4 Virtue Ethics and CRISPR

I have proposed that virtue ethics may be a viable theory for navigating the ethical challenges of gene editing and the use of emerging gene editing technologies. Virtue ethics, being character based, claims that we would know which virtues to employ in a moral dilemma, and we would know this by applying wisdom to the situation, instead of following a set of moral rules. There are several reasons why virtue ethics should be considered as a method of informing decisions around the ethical issues involved with new gene editing technologies such as CRISPR.

3.4.1 Exploring Virtue Ethics as a Viable Normative Theory is Academically Advantageous

Rosalind Hursthouse makes the claim that aspects of virtue ethics are underrepresented in normative ethics, particularly the idea that human flourishing needs to be interpreted in terms of parameters that imply a nuanced understanding of human nature, in a way that a neutral, 'matter of fact' viewpoint cannot capture (Hursthouse, 1999, ch.8).

The emergence of contemporary virtue ethics as a viable normative philosophy suggests there may be untapped resources regarding how one may use virtue ethics in modern moral decision-making. Axtell and Olsen (2012) describe a resurgence of virtue ethics in the field of applied ethics since the 1970's, where consequentialist

and deontological theories have previously dominated the discussion. Therefore, it is academically advantageous to explore and test its possibilities in practical application to novel ethical challenges of the likes presented through CRISPR.

Further investigation of virtue ethics in practice may provide some clarity or alternative solutions. Even if it ultimately transpires that virtue ethics is not the most viable theory with which to approach the ethical challenges of gene editing alone, a deeper discussion into its possible practical application in gene editing creates an opportunity to expand and enrich the debate.

3.4.2 Virtue Ethics: Robust Against a Background of Change

The agent-centered approach over specific rules for action is the distinguishing feature of virtue ethics that allows a moral agent to rely on character traits, giving flexibility regarding which specific actions to take depending on circumstances. A focus on the cultivation of virtues as opposed to following specific actions may allow agents to act in a variety of ways in any given situation and still be considered to have performed a right or moral action. In this way, the agent becomes flexible in decision-making, even in complex dilemmas without complicated rules or fixed obligations. This feature is particularly pertinent given the unique and unprecedented challenges we face with developing gene editing technologies. Approaching such challenges armed with virtues allows for the kind of flexibility that can adapt to the particulars of the given situation rather than having to adhere to a specific rule.

In adopting a flexible, character-over-rules based theory of moral action, individual decisions might vary in different settings and times even when the core values and virtues remain stable. In this way, the theory is not compromised. With virtue ethics, instead of having a rule book for action guidance, one has something more akin to a toolkit of internal values that can be employed time and time again in a variety of situations.

3.4.3 Character Exemplars

Another advantageous feature of virtue ethics is that of character exemplars. If an agent is faced with a moral dilemma in which they are not equipped with the virtues necessary to make a good choice on their own, they are able to consult with other

agents, known to possess more developed virtues than themselves. This allows the agent to act virtuously despite lacking in perfect virtuousness. This makes virtue ethics accessible to a wide range of agents, even if the agent has not had the opportunity to develop the virtues in themselves to a perfect standard. In this way, virtue ethics can be seen to be collaborative over an individualist theory.

3.5 Considering Consequentialism and Deontology

I have discussed some of the reasons for including virtue ethics as a viable normative theory in dealing with the ethics of gene editing through CRISPR. I will now compare how it stands up alongside some of the more dominant normative theories, lending support to my thesis of incorporating virtues into decisions on complex gene editing cases.

In the interest of brevity I will summarize the basic principles of two major normative ethical theories, namely consequentialism and deontology, in broad brushstrokes, going on to explain why they are, on their own, not up to the task of dealing with the unique ethical challenge of current gene editing technology. I will show how virtue ethics can be used to fill some of the gaps identified in consequentialist and deontological approaches.

3.6 A Consequentialist Approach will not be Adequate on its own:

Consequentialism asserts that an action can be deemed morally right or wrong based on the consequences, or outcomes of the act. For the consequentialist, the intent or character of a person is not what determines a person's morality. It is their actions, and the resulting consequences alone that matter (Scheffler, 1982).

Early utilitarians such as Jeremy Bentham and John Stuart Mill claim that an act can be considered morally right if and only if it maximises pleasure over pain (Kagan, 1998, 17–22). Therefore, the measure of whether an act can be considered right is when the net result of the action maximises the positive minus the negative consequences for moral agents in a given situation (Moore, 1912, ch. 1–2.) The utilitarian holds the view that when assessing an act according to its consequences, we should consider which action most contributes to wellbeing. There are of course many views regarding what constitutes positive and negative outcomes. For example, hedonists consider 'good' to be what is pleasurable and the 'bad' to be pain.

The next section will outline several main criticisms of consequentialism as an adequate approach alone to ethical issues around emerging gene editing technologies.

3.6.1 The Measure of Utility is Unclear: What will Future People Want?

By working within a formula focussed on calculation of utility, the Act consequentialist encounters an admittedly well known epistemic problem of knowing what measure of utility use (Hull, et al., 1973). The highest utility could be based on economics, happiness, health, or some other measure entirely. When considering CRISPR, the measure of utility, or what we think will hold positive value for people becomes unstable. For example, if we could make humans more intelligent through CRISPR, this may seem like it would equate to positive utility, but we could not confidently claim that higher intelligence would lead to an effective increase in utility, considering we would be changing humans as we know them today. By focussing on cultivating values such as 'kindness' instead of utility measures like 'happiness' the virtue ethicist avoids having to provide an account for what will be considered positive utility. The virtue ethicist can also be more confident that 'kindness' as a character trait, manifesting in a variety of ways in the external world, will be important regardless of changing circumstances within and around humans over time.

An important difference between happiness as a measure of utility and virtues such as kindness is that the latter are inward states instead of outward occurrences to be measured. Internal character states cannot be measured, nor do they require measurement. Being asked to cultivate kindness in oneself does not require the ability to quantify and compare degrees of kindness. What matters is that a person is simply 'kind'. The effects of kindness could be measured in some instances, but this is not the basic requirement for being virtuous. Because virtue ethics is not wholly predicated on measuring utility, it has some resilience as a normative theory against an ever changing ethical backdrop and may go some way to fill the gap presented by the measure of utility problem within consequentialism.

There is possibly an argument for consequentialism being 'values-driven' but not explicitly so. Consequentialists may respond that the concept of happiness as a measure of utility is also enduring and will also manifest in different ways. However,

there are questions around our ability to predict what will be considered as representing positive utility in the future, particularly if gene editing has the potential to make fundamental changes to human beings. Alternatively if we say "be someone who is kind", what kindness looks like is immaterial, but being a kind person is still valuable to society.

Consequentialism is bound by the requirement to figure out what will cause maximum utility. It is plausible to assume that people will still value justice or kindness in the future but it is more difficult to predict people's measures of utility. Not confidently knowing what others want or what others may want in the future is a standard, but valid concern for utility calculations. In the case of gene editing however, we are considering altering the people themselves, and CRISPR is changing the game at such a rapid pace, so the potential for a disconnect between preferences for humans today and future humans will likely be markedly increased.

3.6.2 The Issue of Consequences

Even if we could set up a consequentialist calculation aimed towards an accurate measure of utility, there remains a significant problem in calculating the consequences. For example, it is unclear how we would anticipate and calculate the consequences of having people with genetically enhanced intelligence. Predicting which actions will produce positive utility through gene editing will not only vary between us and other populations, but it becomes even more complicated to determine within the context of gene editing as we are actively changing what the future moral agent will be like. It is possible that engineering such an advantage amongst a population of people could lead to greater socio economic consequences, such as widening wealth gaps between those who are better qualified for certain jobs or who are able to perform at a higher level in certain industries.

Because gene editing involves changing humans, accurately predicting or quantifying the consequences of such changes is a monumental task, one that would be impossible to accurately determine. This brings forward the question of whether increased human intelligence, as just one example, could bring us closer towards utopia or tyranny. Furthermore, it would be difficult to predict which one of these outcomes may occur. Saying we should do something if the outcome will increase happiness for example, just cannot be accurately assessed. With the social

environment becoming increasingly unstable due to the fact that gene editing is altering humans, calculating consequences becomes increasingly difficult.

There is also the possibility that poorly regulated gene editing could result in a consequence that is ultimately completely destructive to humans. Balancing that scenario with other outcomes is therefore impossible. When the stakes are that high, the calculations are automatically swamped by the possibility of total destruction.

Even though consequentialism is very sophisticated and in many cases a useful normative view, there remain concerning gaps in the theory when we are considering making decisions on CRISPR applications. Consequentialism is, in many cases, an effective theory for making judgements of utility based on *known* parameters of pain or wellbeing but when these parameters are increasingly flexible and even unstable, consequentialism encounters a significant problem.

This is not to say that we should not be considering consequences at all in our decision-making processes for gene editing. It becomes problematic when the basis of our decisions rests on predicted outcomes, particularly in situations for which we may have no similar past outcomes to refer to for consequentialist calculations. Basing decisions on arguably more stable inward character traits or values, shifts the aim of applying gene editing decisions from being focussed on outcomes, to observing character traits aimed at human flourishing overall. Consequences are a factor, but should not be a main driver of decision-making for gene editing when the parameters of such calculations are difficult and sometimes impossible to accurately determine.

Therefore, it does not follow that we should adopt a normative ethical theory that is perfectly prescriptive as it is not functional for everyday life, especially when what is 'known' about life is changing, even at its very foundations. The practicality of consequentialism relies heavily upon our collective inheritance of centuries of accumulated moral wisdom about how to maximise utility in the "*known* human environment." (Vallor, 2016, p.19). In particular, Act Utilitarian calculations require the presence of 'knowns' or some concrete parameters in order to even set up a calculation of utility. Gene editing challenges these knowns, these previous concrete parameters, increasing the difficulty in setting up determinants of action guidance.

3.7 A Deontological Approach will not be Adequate on its own

Some who reject a consequentialist approach may look to deontology as a basis for decision-making in gene editing applications through the likes of CRISPR. Deontology holds that what determines whether an action is moral is based on the rule that produces the action. Immanuel Kant is regarded as a figurehead for Western deontological philosophy. Kant asserted that morality comes from adhering to an overarching moral rule he called the 'Categorical Imperative' (Williams, 1968). Kant described the Categorical Imperative as a standard, objective and necessary principle that must always be followed, regardless of the circumstances or any desires we may have to the contrary. Kant asserted that all moral requirements are justified by this principle, therefore all actions that violate the Categorical Imperative are immoral (Williams, 1968). Deontology assesses the choices of what we do based on notions of what we ought to do rather than guiding what sort of person we should be or what the consequences of our actions should be (Isenberg, 1964). Deontology uses moral rules to determine right from wrong, such as 'do not lie', 'do not cheat' or 'do not kill'. Because deontology requires that a person does their moral duty by following these rules for behaviour regardless of circumstance, it is said to be relatively simple to apply (Isenberg, 1964).

For example, the deontologist may assert that taking another person's life is never right, even in self defence and lying is always wrong, even if it is done to protect someone's safety. The idea that choices cannot be justified by the effects regardless of how much positive utility they may generate puts deontology in opposition to consequentialism as a normative theory. The deontologist would consider some actions to be right simply by the level at which the moral norm is adhered to, even if the act does not maximise the good in consequence (Scheffler, 1982). Deontology relies on the strict adherence to certain moral obligations both to the agent themselves (Agent-centered Deontology) and to others (Patient-centered Deontology) (Kamm, 2007). When faced with unprecedented moral dilemmas, such as those which CRISPR will likely bring to fore, it could be tempting to adopt a specific and simple to follow set of rules on the subject. This seems like it could offer a measure of certainty in ethically uncertain terrain.

However, a deontological approach comes up against some significant issues within the context of gene editing. The circumstances requiring moral decisions continually change across cultures and over time. Once we introduce new ways for human

beings to be in the world, ways that we can create within ourselves through CRISPR, moral absolutes quickly begin to lose their relevance and reliability. In a similar problem to the one presented against consequentialism, if we change humans, then it is increasingly likely that rules suited to humans today may not be suited, or even remotely relevant to humans in the future, depending on how much human life differs from what we know today through gene editing. Something like 'do no harm' becomes increasingly difficult when the ability to affect and manipulate biology in many different ways is now more open and complex. For example, manipulation of a genome to eradicate Achondroplasia (a type of dwarfism) may be seen as 'killing' of a certain characteristic or kind of person. As stated in Chapter 2, there are groups who fear that their very identity as determined by their DNA is now being threatened, and in the future, others like them will no longer exist. Against a backdrop of rapidly advancing gene editing technologies, such moral maxims become difficult to interpret or apply in such an ethically complex environment. If one was to follow a deontological set of moral rules, it may be that these rules would need to change, or new rules would need to be added to maintain relevance in a vastly different society.

Because virtue ethics is based on internal values, rather than rules for action, it avoids the trap of having to modify or create such rules in response to changing external circumstances. Virtue ethics incorporates space for circumstantial change without having to modify a code or rule system. Instead, virtue ethics claims that moral principles codify in very general ways as patterns of reasoning by virtuous persons.

Difficulty in applying moral maxims could lead to either too much discretion or an overly blunt response to ethical decisions. A system of rules will be difficult to apply regarding something so personal as one's genetics, across multiple cultures. A rule based approach relies on an assumption that people generally have similar views about what would constitute a good society, with such views stemming from individual wants and needs. However, moral maxims are products of inherently imperfect societies and with gene editing, may soon no longer be universally applicable. The inflexible moral maxim thus becomes both too vague in one sense and too rigid in another when practically applied.

Shannon Vallor discusses Immanuel Kant's moral rule system as highly abstract and overly generalised, telling us too little about the true shape of modern moral life. It is unclear whether the dutiful deontologist could imagine a future where we can

radically modify the human genome through CRISPR and where any of these possible worlds could be clearly envisioned to guide a person's will (Vallor, 2016, p.16). If even a fraction of the possibilities of the uses for CRISPR are considered, the practical uncertainties will likely overtake the moral rule of the deontologist, stalling consistent rational moral action.

With an approach based on virtues rather than moral rules, these liabilities can be mitigated. Using a revised set of moral virtues brings us closer to being able to accommodate for the values that are likely to remain important for future generations, even genetically modified ones. Virtue ethics is not precisely action guiding, but it allows for more flexibility in action without having to change its core theoretical structure. It may be that some general rules are useful in gene editing applications, however virtue ethics may offer the flexibility that is lacking in a purely deontological approach.

3.8 Virtue Ethics as a Toolkit for Morally Right Action

As discussed, there are good reasons to consider consequentialism and deontology in our approach to CRISPR. However, I have highlighted that there will still be gaps in applying these theories in practice to this issue. There is a need for a novel approach to how we make decisions based on the unique ethical challenges we are facing through CRISPR.

Virtue ethics does not necessarily claim to be specifically action guiding, but neither does it claim that it must be action guiding for it to be a useful ethical theory. It can inform our actions but not prescribe them specifically. This is a main point of difference between virtue ethics, being character based, and consequentialism or deontology which are based on external rules and formulas. The rapidly changing situation advanced through gene editing technologies such as CRISPR creates a challenge for setting specific rules for right action. It seems right that in order to have a guide to action, there is a need to at least supplement prescriptive formulas for 'utility' with a framework based on principles such as what virtue ethics offers.

Virtue ethics is a normative ethical theory that offers flexibility, can accommodate for uncertainty and allows people some freedom to explore a variety of outcomes in action that are all morally 'good' or 'right'. I advocate for an ethical 'toolkit' over an ethical 'rule book'. This ethical toolkit takes a systematic approach consisting of a

collection of virtues specifically chosen for relevance in making ethically sound policy decisions relating to the use of gene editing technologies such as CRISPR in humans. The goal is that this ethical toolkit will be employable in a variety of situations to do with gene editing for which we have no clear way of predicting outcomes. The proposed toolkit will give structure and integrity to our actions by grounding them in specific virtues, but it will allow for a number of specific actions to any particular dilemma that are deemed 'right', or in the interests of promoting human flourishing.

3.9 Relativism and Virtue Ethics

As noted earlier, one criticism leveled at virtue ethics is that it is too flexible or not action guiding enough (Hursthouse, 1999, ch.1). However, virtue ethics retains a sense of structure and integrity due to the framework of clearly defined principles that can be applied to a multitude of circumstances, allowing for right action even if the specific action differs according to the circumstance. Adapting our ethical decisions based on intuition alone would lead to difficulty in defending these decisions based on consistent grounds. It is necessary to be able to update our views and regulations to new and changing situations, but it is equally necessary to adhere to a solid theoretical foundation for this. The kinds of questions that need to be addressed for the use of gene editing technologies are not the yes or no, right or wrong kind of answers, but more nuanced questions like, "in what ways will gene editing change us? How might it hurt or help us? What does it mean to be an enhanced human being?' These are all the kinds of value laden questions that virtue ethics is exactly equipped to help us deal with. Gene editing will change humans, therefore the implications of what is the 'right kind of human' becomes important in a way that we have never had to face before.

Therefore, for gene editing, being less prescriptive is not so much a problem with the theory but a feature. Virtue ethics is not prescriptive but it does have common teleological value in that it aims for the attainment of a flourishing life through developing a virtuous character. Having an account of a virtuous character grounds the theory, preventing it from becoming overly relativistic.

3.10 Against 'Value Free' Decision-Making.

Moral decisions on gene editing are complex and emotional, particularly when facing the possibility of altering humans. Attempting to apply a formula or make decisions on a purely rational basis, that is, removing bias and emotional motivations, is not the right parameter to be working with because this is a discussion about what it means to be a human. The effects of gene editing in humans are more complex and far reaching than economic impact or even life and death. Gene editing deals directly to the issue of quality of life and our individual and collective ideas of 'flourishing' as a human. This can include those things that cannot be measured or quantified in a formulaic way. To attempt to make decisions relying primarily on rationality is to pretend that these emotional value judgements and biases do not exist or do not matter.

A study by Jan Nielsen (2012) discusses how individuals will often invoke scientific fact in moral decisions that are value laden. Nielsen uses examples of discussions around decisions dealing with gene editing which are inherently value laden, allowing for bias to creep in to the decision-making process. Given that values and bias are involved in these decisions, Nielsen (2012) recommends that researchers apply analytical frameworks that are able to take into account the dialectical aspects of reasoning and moral decision-making. Vallor (2016, ch.1) states that the impact of the unconscious mind and cognitive biases on moral behaviour is entirely compatible with virtue ethics which already regards moral behaviour as imperfect and variable within contexts. Explicit acknowledgement of emotions in decision-making is to be accepted and managed rather than ignored or mitigated. This gives decision-makers a more nuanced and complete picture of each case in order to make a decision.

Furthermore, when unconscious bias can be discovered it can be managed by a range of compensating moral and social techniques. Virtue ethics is transparent about acknowledging the role of emotions, culture and values in the decision-making process. Virtues are, and must be, grounded in a particular context. Virtue ethics acknowledges that ethical issues are human issues, full of human complexities, making it difficult to justify a claim of complete impartiality in moral decision-making.

It is necessary to incorporate and acknowledge culture and values as an integral part of the decision-making process, not something to be set aside. Including an awareness of the complex psychological processes in our decision-making around technology allows us to be conscious of their effects in our policy formation.

It would be beneficial, when applying technology that would directly affect humanity as it engages with it at a fundamental, genetic level, that we employ an ethical toolkit equipped to deal with such situations. This includes the ability to acknowledge and make explicit such biases and assumptions that underpin ethical decisions. Including such complex psychological processes in our decision-making around gene editing technology may allow for more holistic awareness of their effects in policy formation. An ethical toolkit based on virtue ethics is a novel and viable approach to ethical decision-making pertaining to gene editing applications, alongside deontic obligations or consequentialist calculations.

3.11 Towards a Modern Virtue Ethics

I have argued for virtue ethics as a viable theory to adopt when discussing the ethical challenges of gene editing, however there remain issues regarding which values remain relatively stable across cultures and over time. There are also questions around how absolute or structured the basic framework should be, and which virtues will be applicable for gene editing specifically. It is crucial to attempt to identify which virtues are necessary to employ in ethical decisions pertaining to gene editing applications such as CRISPR. This will require identifying a position that is broad enough to be widely acceptable but specific enough that it's not empty in practical application. The case for developing a virtue ethical system for gene editing and CRISPR is made more difficult because it requires an attempt to be in accordance with future generations' values. I accept that the criticisms of virtue ethics being lacking in specific action guidance is significant and requires a response. In the subsequent chapters I will consider the practicalities of deploying virtue ethics and suggest ways to overcome this particular concern.

Chapter 4: Developing a Toolkit of Virtues

In this chapter, I will develop and defend a toolkit of virtues regarding human gene editing applications that I see as especially pertinent to decision-makers in Aotearoa New Zealand. In order to do this, I will first expand on the concept of human flourishing and what it might mean to live a 'good' life. I will then discuss and compare a classical virtue ethics list of essential virtues with a more modern take on virtue ethics, showing how they may be applied to the use of CRISPR, based on the unique ethical challenges already identified, and with an acknowledgment of significant future unknowns. Finally, I will develop a toolkit of essential virtues for decision-makers in Aotearoa New Zealand, motivating these virtues from within a framework of indigenous perspectives.

4.1 Human Flourishing: A Good Life

The first step in developing an essential toolkit of virtues is to ground them within a specific structure, so as to avoid falling into the trap of 'making it up as we go along', or relativistic thinking. It is important to have a clear understanding of what is meant by eudaimonia in this context in order to examine and choose the relevant virtues for approaching gene editing decisions.

There are various views on what human flourishing actually looks like in practice amongst the virtue ethical theories. This makes it difficult to determine whether there can be one unified account of 'the good life' that will have a broad application. It seems important that we find such a robust account, given how deep and widespread the effects of CRISPR might be. If some foundational common ground can be found, then this might increase confidence in the approach.

It is therefore necessary to attempt to identify some common features amongst virtue traditions, pointing out whether there are some shared ideas about the human good or the virtuous person. So far I have noted a concept of the good life, as described through Aristotelian eudaimonia. There are alternative conceptions of human flourishing to be found in virtue based traditions across different cultures. In developing her list of virtues, Shannon Vallor (2016), outlines the main concepts of three classical virtue traditions referred to in chapter two of her book, *'Technology and the Virtues: A Philosophical Guide to a Future Worth Wanting'*. In later sections I will discuss the particular list of virtues she espouses for the management

of emerging technologies. First, I will outline the key tenets of flourishing Vallor bases her list on, drawing common key elements regarding human flourishing on which to develop essential virtues that guide a person to this aim.

First, Vallor examines Aristotelian virtue ethics, discussing flourishing in terms of eudaimonia which is cultivated through the individual habitual practice of virtues in action, using character exemplars as a guide in developing these virtues to their full expression. Having already discussed Aristotle in the previous chapter of this project, I will simply highlight that a key feature in Aristotle's idea of achieving eudaimonia is that it is viewed primarily as an individualistic process.

Second, Vallor discusses Confucian ethics. Classical Confucianism maintains a stable core centred on the need for the cultivation of moral virtues to enable harmony within family relationships which gradually extends outwards to the wider community and promotes political flourishing. Confucians were concerned with the nature and psychological structure of virtues, particularly those focussed on fostering and upholding harmonious human relationships (Birdwhistell, 1989). Unlike Aristotelian virtue ethics, the Confusian self is interconnected and not isolated. It is defined by reciprocal obligations to others. Achieving harmony with *The Way (Dao)* is the Confucian ideal for the flourishing human life.

This is said to be achieved through the practice of rituals which express attitudes of respect and deference in everything from familial conduct to dress and presentation (Vallor, 2016, ch.2). This however is not to be conflated with blind following of ritual but is instead embedded in developing a sensitivity to people's needs within various contexts. There is a notable similarity between the idea of human flourishing through habitual cultivation of certain virtues between Aristotelian and Confucian ethics. However, the key difference is that Confucianism prioritises family relationships where Aristotle is more agent centered.

Finally, Vallor comments on the idea of flourishing within Buddhism. Buddhism views the ideal human life as one that seeks to attain Nirvana, a transcendent state in which there is neither suffering, desire, nor sense of self, and the subject is released from the effects of karma and the cycle of death and rebirth (Bodhi, 1984). According to Buddhist philosophy, all beings are causally connected and suffering can be transcended through a cycle of rebirths, eventually reaching nirvana or enlightenment (Vallor, 2016, ch2).

Buddhism upholds demanding ethical values, such as the Four Noble Truths and the Noble Eightfold Path (Bodhi, 1984). However, Buddhism recognizes the need to adapt those values to the changing circumstances of the real world. Similar to Aristotelian virtues and Confucianism, at the core of Buddhism is guiding one to becoming the right sort of person, living in a way that is worthy of human aspiration. The principles found in the Four Noble Truths and the Noble Eightfold Path are therefore a guide towards that goal. It is not just the rituals and practices that are important, but the ability to connect intelligent awareness to such practices within a variety of contexts. It is not just the action that matters but the spirit in which it is performed which is considered truly virtuous or noble.

A similarity between Buddhism and Aristotelian virtue ethics is the use of character exemplars such as the Buddah, who is seen to have attained enlightenment and can thus guide others towards it. However, Buddhism differs significantly from other theories in the type of principles they uphold. For example, Buddhism upholds humility, detached equanimity and compassion, whilst Aristotle upholds warranted pride, appropriate ambition and righteous indignation. Furthermore, Buddhism is concerned with relieving suffering for all creatures, whilst Conficiansim focuses on the familial relationships more highly than on the wider natural world. This apparent detachment from wealth and earthly possessions stands in contrast to Aristotle's view that poverty and material lack are obstacles to human flourishing (Vallor, 2016, ch.2).

It is clear that there are differences in the precise interpretation of what leads to ‘flourishing’, but there is a shared idea of a good, moral life amongst cultures and throughout time based on certain virtues cultivated through habitual practice. This common goal of human flourishing is the reason for cultivating internal virtues across these systems.

Vallor asserts that the internal character cultivation necessary to living a good, flourishing life is a process that happens within a shared context, through our interactions with others in our communities. Acquiring and developing virtues is not an isolated process, even if Aristotle’s version seems to point more to an individualistic view. But even with an idea of common goals for virtuous living, there remains the question of which actual virtues are agreed upon for achieving this goal. For example, it is difficult to assume and assert that everyone believes in the

fundamental importance of being courageous. There are some core theoretical ideas which underpin virtue theory, but when it comes to discussing particular virtues that are most important to cultivate, there is much more room for debate.

However, I do not see this as a problem, but a feature of the theory in its flexibility. By giving virtue ethics a foundation in the shared theoretical commitments of flourishing, one can allow for specific virtues to be given greater or lesser importance than others across varying cultural and historical contexts. For example, an unprecedented moral dilemma regarding a specific genetic enhancement with unclear long-term consequences may require a greater degree of flexibility in thinking of novel solutions and courage in taking decisive action, more so than civility or kindness. This is not to say that these latter virtues do not play a role. However, with a shared understanding of human flourishing as a framework, the virtues can be employed to varying degrees depending on the circumstance at hand.

It is highly doubtful that Aristotle was thinking about a world where issues such as artificial intelligence or the editing of the human genome were possible. However, because of shared commitments towards the idea of a flourishing life, modern philosophers such as Shannon Vallor could use Aristotle's virtue theory in the grounding and development of virtue ethics in a modern context. It is therefore my aim to develop the theory in such a way that it can be applied more specifically to the issue of gene editing technologies while retaining the theoretical backdrop of human flourishing. This will also be directly connected to the need for a stable core theory of human flourishing to anchor the virtues against the rapid changes we will likely encounter in the near future through CRISPR.

4.2 Considering the Virtues

I have chosen to discuss and compare Aristotle and Shannon Vallor's virtue lists because Aristotle is considered the founder of classical virtue theory, at least from a Western perspective. Shannon Vallor is a modern philosopher who has incorporated Aristotlelian virtues, Confucianism and Buddhism into her approach. Furthermore, Vallor has tailored her list of virtues to be applied in a modern context. She particularly emphasises the virtues required for dealing with the ethical challenges of technological advancement more generally, including increased surveillance, social media, artificial intelligence and gene editing. As well as examining these previously proposed lists of virtues, I will use a theoretical basis incorporating the

key notion of eudaimonia, because it serves as a foundational purpose of acquiring and practicing virtues. Finally, turning my focus towards a local context, I will discuss concepts within Tikanga Māori, using this to structure my approach on how decision-makers may apply these concepts to gene editing applications in Aotearoa New Zealand.

4.2.1 Aristotle's List

In spite of the comments on how Aristotle's theory can be used in a contemporary context, there are some problems with trying to import Aristotle into modern technological ethics. When considering Aristotle's list of virtues, there are immediately some virtues that can be set aside and some others which may be more succinctly combined into one virtue. I acknowledge that I am also judiciously interpreting the virtues of Aristotle for a more modern technological setting, specifically the setting of gene editing through CRISPR. However, given this, it is interesting when exploring Aristotle's list just how many of his virtues do still hold relevance. This is an example of how virtues can be relatively timeless and applicable across a variety of contexts. I will comment on those which I wish to incorporate into my own toolkit of virtues for decision-makers and give reasons why they should be included.

First, Aristotle's list of intellectual virtues, being *Nous* (intelligence), *Episteme* (critical reasoning and factual analysis) and *Sophia* (theoretical wisdom), are all baseline requirements for decision-makers regarding gene editing recommendations. Decision-makers need to possess a fundamental ability to think critically, reason with others, analyse facts and evidence, applying knowledge and experience from their respective fields of expertise in an appropriate manner to the ethical dilemmas that arise through gene editing technologies.

Second, the virtues which I believe are less relevant to the context of gene editing practices more specifically are the following: *magnificence with great wealth and possessions, magnanimity with great honours, wittiness in conversation* and *modesty in the face of shame or shamelessness*. This is not to say that these virtues are not relevant in other contexts, but for the purposes of finding a key set of virtues for decision-makers, or those tasked with designing and implementing policy regarding gene editing procedures, I believe there are others which hold greater relevance.

Looking towards the remaining moral virtues on Aristotle's list, there are some which are particularly significant and relevant to decision-makers on their own and others which I suggest are better encapsulated into a single concept within the context of gene editing.

1) Courage in the face of fear, temperance in the face of pleasure and pain.

Decision-makers will need to embody the correct levels of risk awareness when faced with unique ethical dilemmas. CRISPR has presented humanity with a rapidly expanding list of moral and ethical dilemmas, many of which will require a level of courage to act without fully knowing the long-term consequences. Courage will be especially important when dealing with moral dilemmas which are so new, because there is not yet a long history of similar situations to draw from. Many decisions will be made as 'firsts'. Aristotle discusses temperance to mean primarily an avoidance of over indulgence in hedonistic pleasures. However, in the context of gene editing, temperance is also necessary as a form of humility to balance courage. That way, decision-makers can make courageous decisions whilst still retaining a sense of proper caution to recognise that developing technology will likely have some unknown pitfalls. There will be gaps in knowledge that need time to be worked through, both in research and in practice and this needs to be kept in mind alongside the emergence of exciting new possibilities for human life.

2) Liberality with wealth and possessions.

In this instance, Aristotle is primarily referring to a kind of generosity with regard to material possessions. However, I see this as being applicable to gene editing in the sense of being generous with sharing information and knowledge. Incorporating an open attitude to information sharing as opposed to encouraging the privatisation and commercialisation of gene editing techniques is useful, for instance if private entities began to consider patenting particular gene editing methods and even particular genes. Increased access to research information has the potential to decrease risk of harm from poor oversight into research practice and monetizing gene editing applications, thereby increasing opportunities to bring thoroughly tested, safer gene editing applications to the wider public, not just those who can afford access to it. Decision-makers should not only be open with their information

sources but encourage and foster solidarity and generosity amongst those working in the field.

3) Friendliness in Social Conduct, Righteous Indignation in the Face of Injury.

These virtues could be tied in loosely with liberality, however, I see them more strongly linked with ideas around civility, justice, empathy and care for the local and global community. Decision-makers should recommend practices that foster equality along political, social and economic lines. Decisions will ideally reflect a desire for justice, care for others and a commitment to using CRISPR as a tool towards reducing existing inequalities, rather than working to serve private interests that could advantage certain groups over others.

The relevance of Aristotle's virtues in moral decision-making for gene editing is testament to the enduring character of virtue ethics. The virtues that have been omitted from deeper discussion here is not a suggestion that they are wrong, rather it is a suggestion that in the specific context of gene editing applications, they may hold less relevance. It shows how virtues remain relatively stable, with their application being varied and broad, across time and culture. This supports the assertion that an ethical toolkit based on virtues is a viable approach to moral dilemmas that society faces through developing technologies, even those which we have not yet imagined.

4.2.2 Shannon Vallor's list

In the sixth chapter of her book, Shannon Vallor outlines what she believes to be the essential virtues to be explored in depth for the flourishing of humans in the technosocial climate, defined as our changing technologies being increasingly "embedded in co-evolving social practices, values, and institutions" rather than being separate entities (Vallor, 2016, p.6). This technosocial climate denotes increased moral challenges we face through rapidly developing technologies. Vallor acknowledges that Aristotle's virtue theory has significant problems and ambiguities, particularly regarding issues of social inequity and discrimination along gender lines. Thus, Vallor advocates for a modern Virtue Ethics that incorporates a more diverse and inclusive range of approaches rather than a single theoretical framework. "We need to cultivate in ourselves, collectively, a special kind of moral character, one that I will call the '*technomoral virtues*' " (Vallor, 2016, p.2).

1) Honesty

Vallor defines honesty as an exemplary respect for truth, along with the practical expertise to express that respect appropriately in technosocial contexts, which include contexts such as the online environment. Vallor states that human flourishing in social environments has never been able to endure without established norms of honesty.

2) Self Control

Defined as the exemplary ability in technosocial contexts to choose and ideally desire for their own sake, those goods and experiences that most contribute to contemporary and future human flourishing. Being self controlled is to reliably and deliberately align one's desires with the good.

3) Humility

Humility is defined as a recognition of the real limits of our technosocial knowledge and ability, and renunciation of the blind faith that new technologies inevitably lead to human mastery and control of our environment.

4) Courage

Vallor defines spiritual and moral courage as the constant renewal of the choice to live well rather than badly, whatever else this may cost us. Technomoral courage is the reliable disposition towards careful awareness and optimism with respect to the moral and material dangers and opportunities presented by emerging technologies. It is especially pertinent today as our choices no longer just affect those around us but sometimes, the entire global community.

5) Justice

Vallor defines justice as divided into two interrelated character traits. The first is the reliable disposition to seek a fair and equitable distribution of the benefits and risks of emerging technologies. The second is a concern for how emerging technologies

impact the basic rights, dignity or welfare of individuals and groups. Justice entails pursuing values of non harm and beneficence with fairness and accountability.

6) Care and Empathy

Care is defined as a tendency to actively foster the good of others to whom one is bound by familial or political ties. Vallor defines “technomoral care” as a skillful, attentive, responsible and emotionally responsive disposition to personally meet the needs of those with whom we share our environment. This is different to empathy. Empathy is the appropriate emotional response as compassion for another person's suffering or need. Care denotes one’s ability to respond to that need in order to alleviate another's suffering or better someone’s life. Vallor argues that possessing empathy without care is not effective in action.

7) Civility

Civility is provisionally defined as a sincere disposition to live well with one’s fellow citizens of a globally networked society; working cooperatively toward those goods that we seek and expect to share with others. For decision-makers in gene editing I see this as interconnected with Justice, Empathy and Care. For this reason I will not be including it as a separate virtue in my own toolkit of virtues.

8) Flexibility

This is the skillful adaptation to change as called for by novel, unpredictable, frustrating or unstable technosocial conditions. For decision-makers in gene editing, this is a particularly important virtue when considering the unknown consequences of emerging technologies.

9) Perspective

Moral perspective is the ability to see how one's own desire at any given moment can be appropriately scaled within a broader picture of others’ desires and values. This is more complex than simply having moral knowledge. For example, one may be able to intellectually process the statement that one’s own needs and desires are not all that unique or important compared to others’ needs in the big picture. This knowledge does not mean that one will actually be able to see the world in that light

when one's own desires are activated at a non intellectual level. For decision-makers involved in gene editing policy, perspective does seem useful, however, I see this as being encapsulated with wisdom, which I will expand more upon in my own toolkit of virtues.

10) Magnanimity

This refers to those who have rightly earned the moral trust of others and who can guide others toward the good, or toward behaviours that promote human flourishing. The magnanimous person would behave such a way that they accept any honours, accolades and authority they have received with a sense of confidence and pride that is free from vanity and excessive self-promotion. For decision-makers, I do not see this as being a strong candidate for inclusion on the list of virtues. This may become a more important virtue in the future as gene editing becomes more integrated into 'normal life', but currently there are no clear character examples for gene editing specifically. Other virtues I will mention offer guidance for decision-makers whilst waiting to acquire further knowledge and experience in this emerging field. There are certainly 'characters' in the gene editing CRISPR world, as referred to in chapter 2, but whether they are to be emulated is still unclear.

11) Technomoral wisdom

This virtue encompasses all the other virtues. Practical wisdom can be seen in the person who reliably puts into practice the other virtues Vallor has listed, to the right degree and in the right time. It is less of a specific virtue and more of a general condition of well cultivated and integrated moral expertise. This virtue is both a separate virtue on its own but it can also be read as the culmination of being in possession of all the other virtues Vallor has listed. What distinguishes wisdom from the other virtues is that it is the key tool in the toolkit of virtues.

Vallor (2016, p.23), discusses the need for *practical wisdom* and *moral intelligence* in virtuous behaviour. Following rules or principles exactly but without any sensitivity to the nuances of emotional responses to some situations requires social intelligence and a keen awareness of the motivations, feelings, beliefs and desires of others in specific situations. Having wisdom means possessing the ability to know which virtues to employ at any one time and to which degree. For this reason I will

expand on this in my own discussion on essential virtues for gene editing decision-makers specifically.

4.3 Cultural Perspectives on Gene Editing in Aotearoa New Zealand

The collection of virtues I propose are based on the characteristics I see as especially important for those who are at the forefront of navigating morally ambiguous or contentious cases where gene editing in Aotearoa New Zealand is concerned.

Thus far I have presented this approach in 'lists' of virtues. However, given the complexity of the issues within gene editing, I propose an even less rigid structure in choosing a collection, or toolkit, of important virtues. My aim in this section is that by looking at the virtues required for decisions in gene editing we will be able to discuss them specifically in terms of how they relate to one another. So, rather than a list of virtues, I propose a toolkit of values which interact with one another to varying degrees dependent on the case at hand. With this structure in mind I will endeavour to select an appropriate set of values that I see as especially relevant to an age of widespread, cheap gene editing, and in particular to Aotearoa New Zealand's approach to this issue.

First, contextualising our global position is important. Whilst part of a global community, the toolkit of virtues I will describe underpin the importance of a local perspective within the wider gene editing debate. Particularly, it is important that the values proposed stem from and remain grounded within principles of Tikanga Māori.

Hudson, et al. (2019), compiled a literature review canvassing the consistent messages of key Māori cultural concepts and values relevant to research on gene editing. The review noted that concepts of whakapapa (genealogy) are of paramount importance within Māori communities. Stemming from this concept, values such as mauri (life essence), mana (power/authority), and kaitiakitanga (guardianship) were further vital considerations. The review also noted aspects of gene editing as being linked to concepts such as kawa (customary principles), tika (the right or correct), and manaakitanga (to care for) for decision-making and policy formation. Concepts of tapu (sacred), taonga (precious), and wairua (spirit) were linked more specifically with the genetic material being manipulated or passed on generationally.

In Māori leadership, a leader's focus is said to be on enabling others to fulfil their roles rather than on self promotion (Roche, 2019). For decision-makers regarding gene editing, this encompasses virtues of wisdom, perspective and flexibility. Good leadership stemming from humility rather than a display of power may offer a fresh perspective on other notions of the meaning of leadership.

I have thus developed a set of virtues identified from Aristotle and Vallor's accounts, whilst being led by Māori cultural perspectives. There are some virtues in these accounts that I believe hold significant importance here. These include honesty, wisdom and courage. There is a certain level of crossover between some of the virtues I have examined, and so these can be combined. The following section outlines the virtues I propose as essential for decision-makers for gene editing cases in Aotearoa New Zealand.

4.4 The Toolkit of Virtues for Gene Editing Decision-Makers in Aotearoa New Zealand

1) Pono (Integrity in Transparency. Encompases Vallor's 'Honesty')

This is reflective of the Māori value of tika, the right way of doing things. For gene editing specifically this may look like appropriate transparency between decision-makers and the information shared with the agents affected by particular decisions and the public more broadly. This includes the requirement to disclose any personal agendas, conflicts of interest or biases that may exist amongst decision-makers. Therefore, a virtue reflecting honest and transparent processes is essential.

For example, if a decision-maker is the parent of a child who has a particular condition and has chosen not to genetically alter their child, they may have a bias towards declining any application from another parent who wishes to edit out such a gene in their children. This is not to say that the decision-maker would be automatically disqualified from sitting on a panel of decision-makers, but they would be required to disclose and seek counsel where appropriate regarding any potential conflict of interest.

Virtue ethics is able to accommodate for emotions within moral decision-making and therefore should be robust enough to accommodate for such issues when they

arise. This virtue also includes having clear and transparent practices with regard to the uses of CRISPR and their observed outcomes. It involves continued oversight into all credible research, including close attention to longitudinal studies that monitor outcomes of gene editing. Decision-makers need to be able to explain to wider governing bodies and the general public the recommendations they make and provide clear rationale behind them. This includes full disclosure of the resources consulted in making decisions and any organisational affiliations that may have been instrumental in the decision-making process.

2) Mōhiotanga: (Creative and Critical Thought. Encompases Aristotle's Intellectual Virtues and Vallor's 'Flexibility')

Creative thought is essential to be able to expand and consider a wide range of possibilities through CRISPR. Creativity in making morally sound decisions in novel cases that arise with gene editing applications opens the way for decision-makers to stay abreast of developing technologies. It also demands that decision-makers stay up to date with the technologies as they develop so that they are able to see how existing policies can be applied in relevant ways to situations as they arise. Decision-makers must possess the ability to think outside of established norms regarding the potential consequences of any applications, particularly in light of the novel moral dilemmas likely to arise in this area.

Creative thinking speaks to a flexibility in decision-makers' ability to handle their approach to gene editing. As there is no handbook of consequences to look to for guidance, decision-makers must possess an ability to skillfully adapt to each new morally ambiguous or challenging situation. A proactive approach is founded on flexibility and an openness to change based on a pursuit of the good. Creative thinking in this context is not about bending rules or twisting truth. Rather, it is the close attention to the realities of our changing environment. Flexibility is connected with creative thinking because the ability to look beyond existing parameters and entertain new possibilities is important for keeping with the pace of gene editing technologies such as CRISPR.

Critical thought is equally important. Decision-makers must possess the confidence and ability to evaluate any creative ideas and proposals with an honest and intelligent appraisal of any known details pertaining to a particular case. This will serve to keep creative thought accountable to rigorous examination. Challenging

previously accepted or habitual processes is important when considering the future of how, and if, we manipulate the human genome using CRISPR.

3) Mātātoa ki te Whakaiti (Courage with Humility. Encompasses Aristotle's 'Courage with Humility', Vallor's 'Self Control' and 'Courage')

Virtues of self-control, humility and courage in the right balance can work together. Courage in combination with humility and self control will allow for a balanced view to risk taking. This requires an acknowledgement that there are potentially real benefits to be had through gene editing, which would otherwise be denied to people. However, this must be tempered with the awareness that we have much to learn about the risks involved and that we cannot be sure of the real world consequences. A balanced view towards progress tempered with humility around the limitations of CRISPR as it develops can therefore be encapsulated within one virtue concept.

I have previously mentioned that within Tikanga, leadership roles begin with humility. This idea is key, particularly when facing the unknowns of CRISPR applications in terms of the consequences, both short and long term. Decisions should be led by a sense of whakaiti (humility), alongside a keen awareness of the responsibility of ensuring human flourishing, and concern for whakapapa. This extends to future generations.

For gene editing, decision-makers need to have the ability to think critically through the possibilities that gene editing brings and employ the correct level of humility and courage in making decisions, not only for the current generation but for generations to come.

4) Tāria te wā Me Kaitiakitanga (Long-term Thinking and Guardianship. Encompasses Vallor's 'Perspective' and 'Self Control')

This virtue holds the need for a patient outlook when looking towards an uncertain future. This long-term perspective reflects the concept of kaitiakitanga, the need for sustainable guardianship (Harr, Roche & Brougham, 2018). Human flourishing extends into future generations and this must be held as a central concern when making decisions on gene editing. A collective awareness that spans towards a value of caring for those who are to come after us, our whakapapa, is particularly important for gene editing, as the ramifications of our actions today will affect others

to come. Decision-makers must have the ability to discern the correct pace at which we integrate CRISPR technology to human gene editing as it develops.

Guardianship in gene editing decisions might include setting appropriate limits on enhancement through editing. This would require a clear definition of what is considered 'enhancement' and oversight of new editing options as they emerge. This is especially pertinent for decision-makers. They will need to recognise that it is unwise to be overly confident in the idea that transcending the natural limitations of our DNA will be for the betterment of humanity. However, decision-makers will also need to avoid an overly pessimistic view of emerging technologies such as CRISPR which could shut down any possibility for appropriate improvement and advancement of humans that may provide lasting benefits.

5) Whanaungatanga (Care for Community Flourishing. Encompasses Vallor's 'Justice', 'Empathy', 'Care' and 'Civility' and Aristotle's 'Friendliness in Social Conduct' and 'Righteous Indignation in the Face of Injury')

Broadly speaking, whanaungatanga situates itself towards a collective focus on other people, whether familial or in wider community but extends these considerations intergenerationally, including acknowledging the depth and closeness of these relationships (Roche, 2019). Whanaungatanga reflects a recognition of a wide range of global perspectives and our unique place in this global community as New Zealanders. This virtue includes the ability to discern and balance the needs of the individual within a local community, and then expand this perspective to a wider global context.

As raised earlier, Aristotelian virtue ethics has been criticised as being elitist and egocentric (Simpson, 1992). Other systems of values are more collectivist, for example, Confucianism presents an account of virtues which emphasises a collective approach but is heavily focused on the collective being 'levelled' or tiered, for example, family first and then progressing outwards to wider community in diminishing levels of importance or priority (Vallor, 2016, ch 2). Buddhism carries a collectivist approach and equal care for all living things, including animals and insects as equal, taking the collective approach to its most demanding point (Valor, 2016, ch2). Similarly, whanaungatanga takes a more collectivist approach, extending care and concern for the wellbeing of the community beyond the individual.

Whanaungatanga provides a space that takes account of collective, complex emotions and human biases that can influence ideas for how we should use CRISPR, from medical intervention to enhancement and prevention of disease. For decision-makers, this is necessary to moderate blunt, overly rationalised or purely economic motivations towards the use of CRISPR, thereby keeping 'humanity' in the human condition and guarding against the juggernaut of systemic processes. Whanaungatanga strikes at the heart of gene editing issues for this reason. It is appropriately focussed on others and includes the perspective of future generations.

Decisions made in favour of using some gene editing applications could drastically improve equity by removing certain inborn disadvantages. However, it could worsen injustice by allowing unequal access to such techniques through economic inequalities which translate into unequal ability at a genetic level.

For decision-makers, whanaungatanga as part of justice is essential. Decision-makers must be able to navigate the interests of both commercial organisations and public access to technology. For example, should a company fund and discover the ability to produce a certain gene expression through CRISPR, they may wish to patent this particular gene for commercial purposes. When considering the privatisation of genetic material, the issue takes on a whole new complexity, one that could arguably be discussed at length in a separate project. However, it is worth mentioning here as a prime example of why comprehensive understanding of justice in terms of distribution of resources is required for decision-makers. Justice is also particularly important when considering the intergenerational ramifications of gene editing. Questions remain as to whether it is morally justified to alter the genetics of those who have not yet been born and if this is an issue of hindering future bodily autonomy.

For decision-makers in gene editing, I see care and empathy to be combined virtues encapsulated within the concept of whanaungatanga. If decision-makers hold whanaungatanga as a core virtue then they will be moved to consider and preserve humanity and human flourishing in an ever changing landscape of genetically modified people. Specifically, this will involve a high degree of care and empathy for those members of society who may be adversely affected by gene editing practices. Decision-makers must work to avoid making decisions based primarily around economic or political pressures.

6) Mātauranga (Wisdom. Encompassing all of the Virtues Including Aristotle's 'Practical Wisdom' and Vallor's 'Technomoral Wisdom')

In this context, I view mātauranga as the ability to discern which virtues to employ in any situation and the extent to which they should take effect. By way of analogy, consider all the virtues as dials on a sound technician's desk. Each dial that controls a specific sound is set to a certain level on the board in order to generate the desired overall sound. The technician is able to discern which dials to turn up or down as the music plays in order to maintain quality sound throughout. Similarly, mātauranga is the ability to know which virtues to employ in making specific decisions and how they might interact with each other in each case. If someone were to be in possession of all the other virtues but not this one, they may be a risk of basing decisions using an improper balance of care and empathy when there should be a greater focus on justice for instance.

4.5 Towards Utilising the Virtue Toolkit

The above set of virtues is motivated by the theoretical core of eudaimonia, both now and with a concern for human flourishing into future generations. A critical analysis of the virtues pertinent to gene editing in humans, specifically in light of developing CRISPR applications is necessary to help build a framework which key decision-makers will draw from. The analysis of the virtues within their cultural and historical contexts serves to situate Aotearoa New Zealand within the debate and allows for the cultivation of specific virtues that will promote human flourishing in terms of whakapapa. A key aspect to note when approaching cases using this virtue toolkit is the relationship between each of these attributes, specifically the level at which each of the virtues is utilised in a particular case. Each virtue will express itself differently in relation to the other virtues and to the case at hand. Depending on the situation, some virtues will play a larger role in the decision-making process whilst others may remain in the background of discussions. In the final chapter, I will develop case examples to demonstrate how having the right mix of virtues in the right degree can help the decision-making process for ethical challenges brought by gene editing applications.

Having clarified what I identify as the virtues required for creating a toolkit for decision-makers to use in morally ambiguous cases, I will now turn to the practical application of these virtues, of which there are two pressing issues. First, how these

virtues might apply to single cases and second, who the bearers of the virtues are. In the next section, I will look to how one might go about selecting the decision-makers and who the bearers of the virtues might be. I will also look to how governance might be structured for such decision-makers. Then I will demonstrate how these virtues might be practically applied through a case study.

Chapter 5: The Problem of Employing Virtue Ethics in Addressing Particular Cases

I have previously mentioned that virtue ethics is less discussed in the context of applied ethics as a major normative theory when compared to more dominant theories such as consequentialism or deontology. Thus, it is relatively rare to have virtue ethics deployed in the context of ethical decision-making for gene editing. A chief criticism of virtue ethics as a normative theory is that it does not give clear and specific action guidance in morally ambiguous situations. In the previous chapter, I outlined my toolkit of essential virtues for gene editing and gave reasons for choosing these virtues. This chapter will illustrate how I envisage these virtues to be applied in a practical setting.

5.1 Structuring Governance: Who are the Bearers of the Virtues?

When considering applying the virtues, it is necessary to first clarify who are the bearers of the proposed virtues listed in Chapter 4, as there are a variety of possibilities. For example, there will be stakeholders in a particular ethically challenging gene editing case. These will be the people who are affected by a potential edit, for example, the person to be edited (the subject), or the parents of the person to be edited, their wider family and community and even future generations (those affected). Second, there will be those who are to make decisions regarding the use of gene editing technologies (decision-makers). Examples include, but are not limited to, doctors, parents or guardians of the affected, or potentially genetically edited agents, the genetically edited agents themselves, hospital boards, ethics committees and government.

In any given scenario, the decision-makers and these other categories may overlap. For example, sometimes the subject and the decision-maker for a specific gene edit might be one and the same person. For the purpose of this project, however, the focus is not on how virtuous the subject is, or might become, but how virtuous the decision-makers are in each case.

Whilst outcomes of decisions may maximise happiness for the subject in a consequentialist sense, this may not always be the case. The practice of exercising the virtues in decisions will be reflected in the outcome, possibly resulting in decreased utility for the subject, should they be declined a certain procedure. The

virtues employed in the decision-making process must be utilised with a mind towards the flourishing of both the subject and those affected.

It may be the case that performing some edits may result in more virtuous people but this is not something that I see could be easily controlled or guaranteed. So whilst the case may involve an individual subject, human flourishing includes a collective view.

As outlined in chapter 2, because there is a lack of adequate policy around rapid, cheap gene editing technology, it seems most urgent to focus on the virtues that key decision-makers need to possess in order to navigate these situations. My proposed toolkit of virtues was therefore chosen with a mind towards the kinds of people that would be required to make decisions on gene editing technologies. I envisage the decision-makers to operate in the capacity of a review board or panel such as what exists in Aotearoa New Zealand today. These individuals will not necessarily be in charge of implementing official government policies, but their role is primarily to highlight the specific moral challenges that arise through gene editing technologies and have the power to make official recommendations to the government. These individuals, as well as possessing knowledge and qualifications in their respective areas of expertise, such as philosophy, biotechnology, law, community and indigenous knowledge, amongst many others, will possess certain virtues that align them towards a common goal of human flourishing.

At this juncture, I will note that this project does not aim to guide decision-makers towards the aim of producing a more virtuous society, however, it may well be that by making virtuous decisions, society would be more likely to benefit. Virtue ethics is not about "maximising virtues", rather it is about the character traits that the moral agent possesses that underpins their decisions. Recalling a problem of consequentialism, that it is incredibly difficult to predict future outcomes, such that we could not quantify those outcomes, it would be a strange move to attempt to predict what will make for virtuous futures as well. Perhaps, forecasting might be more closely aligned with very generalised, top down principles at government level, in as much as they can attempt to predict long term outcomes, such as eradicating less controversial diseases. This shows that there may be other normative systems at play in decision-making, such as consequentialism. However, the assertion is that virtue ethics should be an integral part of how we approach challenging ethical cases in gene editing applications.

Employing a virtues based framework will help to deal with the unique challenges raised by gene editing in humans by grounding ethical dilemmas to a foundational set of values by which actions can be taken. It allows for a variety of specific actions and outcomes, however, the virtues themselves will be the measure by which these decisions are to made. The decision-makers, having a clear understanding and practice of these virtues will be able to base their decisions on these virtues and determine, through collaborative discussion, recommendations toward policy and law.

5.2 Putting Virtues into Practice: The Action Guidance Problem

When considering an ethical approach to applying gene editing technology in the use of CRISPR, I have discussed the reasons why a rigid, external rule based system is inadequate on its own. I have argued for a system that can incorporate flexibility in an ethical theory based on internal principles. However, I acknowledge that one of the main criticisms leveled at virtue ethics is the claim that it is not sufficiently action guiding, leading to possible difficulties in applying it to specific, morally ambiguous cases. This criticism requires addressing specifically in light of the uncertainties that already exist and continue to emerge regarding morality and gene editing. I suggest that a novel approach to this complex issue may lie in combining virtue ethics with a framework specifically focussed on decisions regarding single cases: Casuistry.

5.2.1 Casuistry

Although similar to virtue ethics in that it does not hold to a specific formula for right action, casuistry approaches ethical decision-making differently. Casuistry focuses on specific details of cases as they arise and gives a method of making practical decisions based on real life situations. The goal of casuistry is to convince stakeholders on a specific issue that one particular course of action is more favourable over others, thereby reaching practical, defensible conclusions over epistemic certainty. The casuist does not aim to justify and advocate for a particular moral norm in any or all circumstances (Jonsen, 1991). This means casuistry is relatively user-friendly, in that it does not require decision makers to adhere to one particular normative theory in making decisions, nor does it require one to refer to others as experts on morality to make ethical judgements (Calkins, 2005).

Once I had largely developed my framework and proposal for this thesis on the idea of combining virtue ethics with casuistry, I found that this concept has been floated before in Martin Calkins' (2005) work, '*How Casuistry and Virtue Ethics Might Break the Ideological Stalemate Troubling Agricultural Biotechnology*'. However, this work has not had much attention in wider literature. Calkins (2005), argues that it is necessary to employ a combination of virtue ethics and casuistry in making gene editing decisions, because there are not yet sufficient historical references for gene editing examples, nor do we have character exemplars who have emerged.

I agree with this assertion and advocate for this approach towards CRISPR applications in humans, because the technology is both new and rapidly advancing. However, Calkins' account offers suggestions pertaining to gene editing primarily for applications in the food and agriculture industry, leaving significant issues pertaining to CRISPR applications in humans unaddressed. Furthermore, Calkins does not offer a comprehensive, structured plan for applying this framework. The account that I am offering provides a more comprehensive framework which is based on a curated set of values specific to human gene editing in Aotearoa New Zealand.

I am proposing second order policy advice, namely that there should be less directives at the first order, government level regarding any specific actions smaller-level decision-makers should follow. In the following chapter I will expand on how this might look. First, I will describe the key features and some issues with casuistry, then show how it might be complementary to virtue ethics in specific cases.

Because casuistry is concerned with finding practical solutions to moral dilemmas based on particular features of each case, it is commonly employed as a method for ethical decision-making within the medical community. Ethically difficult decisions are approached in a specific series of steps, beginning with the particular case in question and adapting what is considered right action to the circumstance. Casuistry can work in conjunction with other ethical theories without being bound by the principles specific to that theory.

Jonsen and Toulmin outline these steps in the process for working through a particularly morally complex case (Jonsen & Toulmin, 1988, ch.16). First, the problem needs to be described in detail, including any specific individual moral

obligations or viewpoints the stakeholders (such as medical patients) might have that could be applied to the situation. This is the 'Morphology' step.

The second step, 'Taxonomy', involves identifying the type of case to which the dilemma belongs, and situating it within the paradigm of existing right and wrong conduct in similar dilemmas. Finally, once the problem has been described and situated within a paradigm of similar types, using practical wisdom, a critical analysis can be carried out and an action decided upon. For example, in a medical setting, a patient (who is a minor) requires a life-saving blood transfusion, but the patient's parents hold strong religious beliefs against such practices. The medical ethics committee would have to weigh up the particulars of the case, compare it to other cases of its kind and decide whether the religious beliefs of the parent should be set aside in favor of possibly saving the child's life through performing the procedure.

The casuistry position is that ethical reasoning must be more practical rather than theoretical, because in practical ethics, the most important considerations must be towards judgements of particular cases, instead of concern for a theoretical or general principle, argued to be central to other normative theories (Tomlinson, 1994). Casuistry focuses on the practical elements of a situation, making it more likely that the patient in each case will benefit directly. By recognising the individualism of the patient, including their medical history, lifestyle and even their beliefs, casuistry gives a tailored approach to ethically difficult situations in the medical field.

5.2.2 Key Criticisms and Problems for Casuistry

There are some key criticisms leveled at casuistry. It's important to understand that casuistry involves giving up a number of standard ideas about how to approach such morally ambiguous cases. For example, casuistry rejects the idea that decisions should be universalized across different scenarios. This raises concerns over relativism, in that ethically inconsistent decisions may result. John Arras (1991, p48) discusses the risk of the casuist slipping into distorted ideology and losing the critical element of analysis. This puts the casuist in a position where they may overlook some difficult big picture issues such as 'What kind of society do we want?'. If one wanted a general approach to gene editing decisions nationwide, casuistry may not appear ideal on its own, because each case is considered based on its

particulars, rather than being subject to a core moral outlook. Furthermore, there are time constraints on developing a new chain of moral reasoning for every situation. Whilst this may work best for individuals, it may not be ideal when looking towards a general approach to morally complex matters such as formulating gene editing policy.

One further difficulty arises in the 'Taxonomy' step, which requires similar cases to compare with. Gene editing through CRISPR is so new that there may not be sufficient, or indeed any past cases to make comparisons with when deciding on a course of action. The moral and ethical issues pertaining to gene editing are very likely to be unique, at least while the technology is so new, and even into the future, as the technologies develop so rapidly. It may be difficult to accrue sufficiently similar cases to form an ethical paradigm.

Despite these criticisms, casuistry is user-friendly, in that it does not require decision-makers to adhere to one particular normative theory in making decisions, nor does it require one to refer to others as experts on morality to make ethical judgements (Calkins, 2005).

5.2.3 The Virtue Ethics-Casuist Approach

At this point, much of the above concern can be addressed by adopting a particular strategy. From now on in the thesis, I turn to propose a framework of second-order policy advice, namely that there should be fewer directives at government level regarding any specific decisions smaller-level decision makers should follow. This means a casuist approach can be utilised on a case-by-case basis by localised committees, where virtue ethics provides the value system and moral guidelines by which decisions should be considered. In turn, this guidance from a normative theory that is substantive in its own right may also mitigate concerns in instances where the decision-making body lacks sufficient comparison cases.

When we consider each case according to its merits, it may still be that there are virtues which enable a decision-maker to think more comprehensively about the situation at hand. For example, if we were dealing with a particularly morally contentious or sensitive case, it would be preferable to be able to think it through with empathy. Whilst empathy is not directly involved in the reasoning process

itself, it may be important for the manner in which the decision-maker engages with the case.

Another way would be to approach morally ambiguous situations as a casuist, but maintaining the idea that the better casuists are also virtuous, or in possession of certain fundamental virtues. Combining the virtues pertaining to gene editing as suggested in the previous chapter would give casuistry a more explicit theoretical base from which to make decisions, particularly in the absence of a large number of past cases to draw analogies from. In exchange, the demand from casuistry that decisions need to be made within a practical and specific framework gives grounding to the collection of virtues and situates them within a practical, real world setting. This lessens concerns around virtues being insufficiently action guiding.

This project carries a focus on individual cases, but I am aware that these cases occur within a wider context and are subject to national policies and laws. Therefore, for approaching gene editing decisions, my suggestion is that the nationwide policy should reflect a stance of utilising virtue ethics and casuistry when approaching particular individual cases. These two systems work together to create a structured framework, grounded in a set of virtues that allows the flexibility to approach individual cases using casuist methods. The next section will discuss how this might be applied.

5.3 Structuring Decision-Makers: From Nationwide Guidelines to Community Groups.

Considering how the decision-makers should be structured and chosen, I will give recommendations as to how decisions might be directed, initially at a national, first-order governance level, on to second-order decision-making levels for individual cases.

Because of the multitude of ethically complex factors likely to be involved in gene editing cases and because the virtue ethics-casuist perspective recommends a recognition of the nuances of each case, it does not follow that there should be a specific government response or all-encompassing decision with regard to specific applications of gene editing. What I suggest is a national response that is committed to adhering to a virtue ethics-casuist approach to cases of gene editing as they arise, devolving decision-making powers more towards second order smaller governance

bodies, such as local government agencies and ethics committees. This guidance should include identifying and highlighting key virtues for decision-makers to exemplify, thus avoiding the moral relativism that casuistry alone is vulnerable to. I accept that at top level governance, consequentialist philosophies often play a dominant role regarding the approach to policy making. That aside, considering the unprecedented challenges we face with the emergence of cheap, user-friendly gene editing through CRISPR specifically, I argue for a shift away from this rule based approach and to one where particular decisions regarding specific cases should be left to smaller governing bodies, with greater ability to respond to unique aspects of those cases.

This might involve the government setting upper limits on how far one can use gene editing in terms of disease cures, through to enhancement techniques. For example, it may be fairly straightforward to look at approving the use of gene editing for cases such as eradicating Huntington's Disease or some cancers from genetic lines. In these situations, the decision seems to be quite clear cut and less controversial. However, when it comes to isolating and editing for conditions such as Achondroplasia (Dwarfism), this may require a more cautious, yet open approach. These more nuanced cases require critical engagement across socio economic, political and cultural lines, more so than for the eradication of a clearly categorised 'disease'. I acknowledge that it is beyond the scope of this project to specify what these exact boundaries might entail, however, the work of the RSNZ Panel on gene editing as discussed in chapter 2 has gone some way to suggest what some of these limits may be when it comes to editing the human genome. It is, however, important to note that the panel has made clear its desire for a regulatory system in Aotearoa New Zealand that has an easily navigable framework with clear and consistent guidelines for assessing difficult cases (Royal Society Te Aparangi, 2019).

With an understanding of the need for what broader, top-down boundaries could look like, the next step is to discuss how smaller groups of decision-makers could be structured. Those groups who would be dealing directly with cases, such as ethics committees in hospitals or research groups, will need to apply a principled approach to specific moral details of each case.

5.4 Second-Order Governance: The Decision-Makers

Once national directives have been established, there is a need to decide what second-order governance should look like. If we are to devolve more decision-making power to smaller governing bodies, the way these groups are selected and structured are of great importance.

As a collective, decision-makers should encompass the virtues of the previously outlined collection in chapter 4, however the degree of said virtues may express themselves to varying degrees within each individual. Therefore, diversity amongst individual decision-makers is vital. Diversity in this context is not simply referring to diversity for its own sake. The diversity amongst these decision-makers must be relevant to the particulars of the case. For example, there must be provisions made for the bicultural context of Aotearoa New Zealand, but also including relevant diversity in relation to the cases at hand. This is not just about accommodating various people's views, it is recognising that the more varied the perspectives involved, the more robust the virtue ethics approach will be, regardless of the issue at hand. A wider range of relevant perspectives may uncover issues that a less diverse group may overlook.

It is also necessary to ensure the various perspectives fit the specific setting, such as the time, place or subject under discussion. So, if the decision-makers were considering a case of editing out the gene for Achondroplasia for instance, there must be provision for those who live with Achondroplasia to be included in making these decisions. This does not assume that those individuals who are included for this specific case are more virtuous, but it does show the importance of being able to apply the virtues at a relevant and practical level with the perspectives of those for whom the individual case may hold great significance and personal relevance.

This is not to say that those who are not connected to the case directly should have no say. All affected agents will be part of a wider community and therefore their interactions with the wider community, must be taken into account. It is not just the agent and their close connections we need to consider, but the broader impact on their environment and society.

Decision-makers should also be selected for their knowledge and experience in the fields including but not limited to, science and technology, philosophy, politics, law

and public health. They will possess a comprehensive understanding of a well understood goal of 'human flourishing'. Those selected should have extensive training in understanding and applying specific virtues in practice, particularly in difficult or ambiguous situations.

5.5 Indigenous Voices

In setting up what the decision-making committees should look like and who should be included within the context of Aotearoa New Zealand, there are some key considerations to be made with regard to cultural perspectives. Olivia Oldham's (2017) critical analysis of incorporation of Māori perspectives in gene editing forums offers some key insights and strong criticisms on structuring such committees. Based on this analysis and considering the way government policy and ethics committees have been structured in the past, there are some key things I wish to avoid in this context.

First, Olham refers to a detrimental, over-spiritualized view of Māori values and concepts within government policy that lends it to being easily sidelined in the fallout of 'rational' decisions.

> "Because of its perceived objectivity and universality, science is able to dominate debates which are culturally deemed to be scientific. Thus, 'unscientific perspectives relating to ethical, cultural and spiritual matters are able to be disregarded or significantly diminished in weight." (Oldham, 2017, p.12-13).

> "The acknowledgement of the current rational scientific bias would open up space for a fair consideration of concerns that don't fit within the dominant paradigm." (Oldham, 2017, p.25).

This approach to Māori perspectives in governance is arguably a potential driver for tokenism within policy. Developing concepts centered on Māori perspectives may go some way to avoiding this issue.

Second, Oldham discusses the failure to adequately consult Māori in both the setting up of policies and in the decision-making process (Oldham, 2017, p.14). She asserts that Māori have been wrongly viewed as advisors to the Crown rather than partners

with the Crown, creating an imbalance of power preventing Māori perspectives from being adequately considered in decisions.

I agree with Oldham in opposing the idea that Māori should be consulted rather than on an equal footing with other decision-makers in the process. From the very beginning, decisions should be made in partnership through diverse and egalitarian representation of each case at hand. Here I recognise that claims regarding the right ways to include indigenous perspective should come from an indigenous voice. I cannot speak with the appropriate level of authority nor assume to know everything about any cultural perspective on gene editing policy in Aotearoa New Zealand other than my own. However, this is in support of my reasoning for having appropriate diversity amongst decision-makers.

Cultural resilience can be encouraged through the mutual recognition of the validity of each culture's body of knowledge and the investigation of the basis of different opinions. This enables knowledge exchange and cultural development. Oldham states that framing decision-making in this way can enable healthy disagreement and conversation, of the likes that has been raised throughout the gene editing debate (Oldham, 2017, p.26). Varying perspectives should be seen as an opportunity to create new forms of knowledge and understanding, which can lead to more productive and positive outcomes.

5.6 Approaching Cases

I have described how virtue ethics and casuistry might be complimentary in decisions pertaining to CRISPR applications in humans. Having discussed how governance of these decisions might be structured and how decision-makers might be selected, I will now turn to illustrate how this might look in practice. I have chosen these particular cases in the following chapter to show how my toolkit of virtues identified in chapter 4, combined with casuistry may be applied. The aim is that this approach will help decision-makers see contentious gene editing issues in a more nuanced and comprehensive way.

Chapter 6: Case Study

When approaching the case studies, it is important to note that this is not an attempt to solve these issues. The primary point is to demonstrate that virtue ethics has a role to play within the context of gene editing technologies in Aotearoa New Zealand. Some of these questions warrant full analysis of their own, outside of this project. The intention is to highlight that individual decisions are best considered in full context, by a group of diverse people possessing a specific set of virtues which inform their moral decision-making.

6.1 Case: Cure or Homogenisation? An Analysis of Huntington's Disease and Achondroplasia (Dwarfism)

As outlined earlier in this project, one of the most promising features of CRISPR is the possibility of eradicating serious diseases from family lines. However, this raises the issue of which conditions are considered 'diseases' in the human genome. The following case outlines how virtue ethics and casuistry can respond to this issue by comparing two conditions, Huntington's Disease and Achondroplasia. The response to one condition appears to be fairly straightforward and I have included this as a comparison with another condition that is significantly less clear cut and contentious, in order to demonstrate how the debate may be seen in a more nuanced way through a virtue ethics-casuist approach.

First, I will outline the issue and set it out within a casuist framework. Second, I will discuss the virtues in relation to the issue, showing how they might be employed in this debate to guide decision-makers. It is also worth noting that in a real case, there will be much more detail than what can be included here. This additional information will be significant and would help to attain a more definite result.

The Neurological Foundation (2019) describes Huntington's disease as an inherited brain disorder that causes cells in some brain areas to die, resulting in mental and physical impairments. This disorder is caused by an expansion of CAG (cytosine-adenine-guanine) repeats in the DNA code. This produces an abnormal protein that gradually causes the gene to malfunction and neurodegeneration to occur. Symptoms can include issues with mood or affect, coordination and movement, loss of speech and eventually dementia and premature death. About one in every 10,000 people has Huntington's, however the ramifications of the disease

are said to affect one in every 1,000, taking into account at risk individuals, caregivers and extended families.

One of the key issues with Huntington's Disease is that a person with the gene mutation most often only exhibits the symptoms later on in life, meaning that a person may reproduce and pass on the disease before they are even aware they have it.

Consider a case of a couple wishing to eradicate the gene for Huntington's Disease based on the evidence of one parent having the gene for it. There is a 50% chance that their offspring will be born with the condition as a result (The Neurological Foundation, 2019). Should they bear a child with Huntington's disease, their offspring will face significant physical, mental and psychological impairments. There currently is no known medical cure for Huntington's. However, the arrival of CRISPR has renewed hope for the eradication of this disease through a selective gene edit in the germline.

Now, consider a scenario of a couple who have a higher than average chance of bearing children with Achondroplasia. Achondroplasia is a common form of dwarfism caused by a mutation in the genomic sequence that results in a glycine to arginine substitution (Miao, et.al, 2019). Physical signs of Achondroplasia are shortened limbs on a torso that is of typical length and in some cases an enlarged head. Complications listed with Achondroplasia can include issues with sleep apnoea, increased risk of cardiovascular disease, lordosis (curved lower spine), poor muscle tone, loose joints, frequent middle ear infections that can contribute to hearing loss, delayed developmental milestones and higher rates of insulin resistance (de Bruin and Dauber, 2016). Through CRISPR, the ability to isolate and suppress the gene for Achondroplasia has been trialled with some success in mice (Miao, et.al, 2019). Researchers are now considering an edit using CRISPR-Cas to 'knock out' this phenotype in the mice offspring.

Depending on one's values and perspective, Achondroplasia might be considered either a disability or simply one way of being human. Rebecca Cokely is a former representative for the National Council for Disability in the United States. She also has Achondroplasia. In her 2017 piece for the Washington Post, Cokely makes the argument that potentially editing the gene for Achondroplasia is a threat to her identity and to the identities of others like her.

> "I am who I am because I have dwarfism. Dwarfs share a rich culture as do most disability groups. We have traditions, common language and histories rich in charismatic ancestors. I can honestly say that I may not have been able to work in the White House doing diversity recruitment for President Barack Obama had I not been born a little person. It allowed me to understand discrimination, isolation and society's lowered expectations." (Cokely, 2017).

6.2 A Casuist Approach

Recall that the casuist approaches cases with a view to analysing the particulars of the scenario in a series of specific steps: 'Morphology', (an outlay of all the relevant details of the case), 'Taxonomy' (comparing it to similar cases or situation it within a paradigm), and 'Analysis' (culminating the previous two steps for a decision to action).

6.2.1 Morphology:

In the scenario pertaining to Huntington's Disease, the parents have the means and desire to eradicate genes for the condition from their potential offspring and in any future descendants. They are aware that the disease is degenerative with no known cure and is genetically inherited. There is evidence that one parent has the gene for Huntington's, so there is a significant chance of passing it to their offspring. Those affected by this case include future generations, other people who interact with the parents and their offspring, those directly concerned with the care of the family including medical professionals and other community service providers. It is notable that some agent's choices will be limited by this decision, particularly the potential offspring in that the edit may (or may not be) be done on their behalf, which will affect their life in future. This shows that the decision-makers will need to reliably account for the preferences of others regarding this issue.

For Achondroplasia, researchers have the ability to isolate and therefore potentially edit out the gene within the germline. Considerations around societal attitudes and interpretations of Achondroplasia will need to be taken into account should parents begin to selectively edit this gene from the germline. It is possible that there are people who would, if given the option, choose to have this edit performed for their

offspring and future family line, possibly even parents who are living with Achondroplasia and who do not wish to continue this in their offspring. From a risk standpoint, there remain concerns around off target effects and mosaicism, although CRISPR techniques are continually being refined and improved for both efficacy and safety. Maintaining the ability to do this with fewer off target mutations is improving.

6.2.2 Taxonomy:

For Huntington's, this type of case fits most closely within the area of human gene editing for medical treatment purposes. Huntington's does not appear to have any possible desirable features. This is a degenerative disease and therefore removal of the Huntington gene is not an enhancement of an otherwise healthy life but a life saving procedure. Additionally, one would be hard pressed to argue for having Huntington's disease as a desirable lifeway.

Without editing Huntington's from the germline, parents who are aware they have the gene can opt not to bear children on the chance that their offspring inherit this disease. There are those who may decide to continue with the option to have children. Should they bear a child with Huntington's, due to a lack of treatment options, other than management of the disease to slow its progression, the potential cure lies in eradication within the germline. The gene for Huntington's can be isolated and therefore potentially edited. There is evidence that by using CRISPR-Cas9, scientists can treat the disease by editing out this gene mutation with a single dose (Eisenstein, 2018). There is also the option to avoid germline edits by suppressing symptoms in a person who has Huntington's using specific edits into the individual (somatically) and slow the disease's progression, thereby not affecting future generations (Budworth, et.al, 2015). The taxonomy parameters for Huntington's are therefore that it can - but does not have - to affect the offspring. With a germline edit, this will lead to complete eradication of the disease in that later lineage.

In the case of Achondroplasia, there are presently no known cases of gene editing to remove the responsible gene being carried out in a human embryo. Unlike Huntington's Disease, it is not clear that Achondroplasia constitutes a harm with no perceivable benefits. More importantly, some people with Achondroplasia see this as just another way of being a human. Given these differences, unlike Huntington's,

some people might later on regret that they were prevented from having Achondroplasia.

Whilst there are no past cases to compare it to, there is a plethora of literature on the subject that could inform the paradigms and concerns of this case. There are cases where it is clear that societal values have determined that certain lifeways are less desirable. The selective termination of foetuses screened for having Trisomy 21 (Down's Syndrome) (Gottfreðsdóttir, & Björnsdóttir 2010) is one example, as is selective abortions of female fetuses in India (Arnold, Kishor and Roy, 2002). These are all performed with a certain idea of the 'better way to be a human' or what 'the better life' is within these cultural contexts. The parameters for Achondroplasia are therefore complex and dependent on individual, cultural and societal views on what is 'the better way' to be a human. That is, one may not necessarily think it is wrong to have Achondroplasia, but still think it is somehow worse than not having Achondroplasia. In this case there are strong arguments to be made as to possible desirable features of Achondroplasia, in terms of personal and cultural identity and social connection. Therefore, it is not clear cut that we are as firmly in the paradigm of treating disease. Thus, there are arguments to be made that editing out Achondroplasia is overstepping personal autonomy of future generations in a way that is more difficult to justify than with Huntington's.

6.3 Applying Virtues

Before moving to the final analysis stage, I will turn to how the virtues outlined in chapter 4 may be applied to the case, showing how they can illuminate complexities and give a broader picture of the issue at hand.

Pono (Integrity in Transparency)

For Huntington's, it seems as though this case is less controversial. However, it is imperative that all potential conflicts of interest are disclosed by all decision-makers and stakeholders in this issue. Eradication of disease does not mean decision-makers should assume that choosing to perform the edit is straightforward. It must first be agreed upon that Huntington's is to be considered a disease without any significant positive features. Full disclosure of information on the case and of all interests of parties involved must be put forward, regardless of the case. Arguably, it is even more imperative that cases appearing to be straightforward at face value

should be closely scrutinised. This serves to mitigate any assumptions or hasty decisions of any involved parties. If an issue appears simple, it may be that there are some significant blindspots and rushed conclusions could be drawn. Transparency is therefore key to proper procedure and due diligence towards any gene editing decisions.

In the case of Achondroplasia, the complexity of the issues makes obtaining a clear and consistent picture of the personal values and potential biases of all stakeholders more difficult. Furthermore, it is important to note that any embryo to be potentially edited, and in the case of germline editing, all the offspring are stakeholders and holding this consideration in discussions concerning transparency is vital. For example, it is likely that decisions of this nature may include strong emotions and a variety of perspectives. Decision-makers would need to gather honest perspectives from stakeholders on all sides of this issue. This includes having transparent accounts regarding what people living with Achondroplasia see as unique benefits and challenges in their lives concerning Achondroplasia. It will also be important to include perspectives of family members and the community of people with Achondroplasia and allow them to express the positive and more challenging experiences with it. An open, inclusive discussion from stakeholders and decision-makers must occur in order to be able to move with some level of confidence toward a moral decision.

Mōhiotanga (Creative and Critical Thought)

In the Huntington's case, it is important to critically analyse any available treatment options aside from the edit itself. If there are alternative treatments in development that include slowing the disease progression or even mitigating some of the symptoms without altering the germline, this must be taken into account, as there may be families that would prefer not to artificially alter their genetics. Although difficult to imagine for the case of treating a degenerative disease, there are those who may view a gene edit of any kind as somehow fundamentally altering or even severing familial connections on a spiritual identity level for example. Even considering that an edit to eradicate Huntington's in a family line would constitute a positive decision, it may be that the family lineage could be viewed as ending in one sense, and a new family line containing altered genetics beginning, rather than the same family line continuing on to subsequent generations. Holding a place for creative thought around the identity of future generations and considering whether to allow for an unaltered gene pool in future seems right. This is an important issue

not to be overlooked. It will also be prudent to critically analyse any reported risks or concerns with performing the edit, both from a medical and ethical standpoint. For the purpose of attaining the correct analysis of the case details and to ensure that broad perspectives from all agents are heard, critical thought is a necessary virtue in this instance.

Unlike Huntington's, Achondroplasia is not clearly a disease or a phenotype that has no positive features. This problematises the issue significantly because decision-makers need to determine whether to view this case as an example of breakthrough technology or one that moves us closer to eugenics. There needs to be serious thought into whether editing the gene for Achondroplasia is advocating for an idealised, 'better kind of person' to be, overlooking the idea that having Achondroplasia may be a legitimate lifeway in and of itself. However, if refusing the edit meant the couple decided to discontinue a pregnancy, that might make performing the edit a potentially life-saving decision. Clear definitions of 'disability' and 'enhancement' will need to be considered and determined in order to critically evaluate the information and arguments presented.

Mātātoa Ki Te Whakaiti (Courage with Humility)

Recognising the potential for risks both known and unknown outcomes is imperative in these cases. Exercising the courage in deciding to perform the edits when they are warranted is important but must be weighed with the humble awareness that all of the possible consequences cannot be calculated. It is already established that CRISPR is still developing as a technology and the possibility of off target mutations remains a concern. Huntington's may be a well understood condition, however there are risk factors involved with gene editing, particularly with germline editing that must be held seriously. A decision to move forward with any procedure, particularly one that affects future generations will always require courage in the face of such risk.

This is also true for Achondroplasia, however, it requires even greater courage, especially when there are some arguments for the unique benefits of living with Achondroplasia. To make a choice either way, being to allow or deny an edit of this nature will take courage because this case is very contentious. Either act will likely cause upset or disappointment to one or more stakeholders. Decision-makers need to have the courage after honest, critical and creative thought and discussion to clearly move in a direction. The consequences of such an edit, particularly in the

long term cannot truly be calculated, therefore decision-makers will need to be in possession of the virtue mātātoa ki te whakaiti. It is worth noting that possessing or being trained in developing this and other virtues will serve the decision-makers well, both in themselves as effective decision-makers. They will be able to make confident decisions without excessive fear or recklessness.

Tāria te wā me Kaitiakitanga (Long-Term Thinking and Guardianship)

Considering the known long term effects of Huntington's, decision-makers would likely err in favour of performing a germline edit. However, it is important that decision-makers consider the whakapapa of the agents in future generations and how an edit of this nature may affect them. Although difficult to imagine, there is still the possibility that some stakeholders disagree with performing the edit on the grounds of preserving the natural family line. However, preserving the family line by means of gene editing could arguably increase the flourishing and health of families both now and into the future. Concerns of this nature must be taken into account, however, when combined with the exercising of the other virtues, it may take a less prominent role for this case.

More contentious issues demand a more nuanced perspective regarding future people and so this virtue will be of greater importance in the case of Achondroplasia. There are positives with regard to culture, social connections and practices amongst those who are born with Achondroplasia that may need to be considered as being aspects of whakapapa to be preserved over the long term, into future generations and held as valuable to future communities. There are also some physical and social difficulties in living with Achondroplasia. This may not necessarily be considered as something to be "fixed" by gene editing. This may be part of a wider discussion around equality and respect for diverse ways of being in society. It is therefore essential to approach cases that are contentious with a view to the wider social aspects at play both now and into the future and evaluate whether a change needs to be made. For example, we may reflect on what the future may look like if the edit was made, or if the edit was not done but instead we considered what changes could be made to society that might mitigate some of the difficulties faced by those who have Achondroplasia. Although it is not possible to fully calculate consequences as a basis of our decisions (as stated in chapters 2 and 3), it is still essential to hold these considerations alongside the practice of virtuous decision-making. The possessors of kaitiakitanga would be effective at including these concerns in the decision-making

process. If a change must be made, it should then be decided whether it should happen in the form of a gene edit or amongst social and cultural spheres.

Whanaungatanga (Concern for Civic and Community Flourishing):

Social and economic disadvantages for the offspring with Huntington's would be an important consideration. Although the symptoms of Huntington's are seen in adulthood and the consequences of the disease progression is death, it is important to note that any treatment, even the likes of palliative care for example may cost the subject, their family and the wider community on emotional, social and economic levels. Given these concerns, the virtue of whanaungatanga, including appropriate empathy and care for both the parents wishes and the high risk of negative effects on the offspring later in life if they are born with the gene for Huntington's should be taken into account. Decision-makers possessing the virtue of whanaungatanga would be better equipped to make a good decision regarding such cases.

For Achondroplasia, whanaungatanga is concerned with acknowledging and discussing the impact a diagnosis of Achondroplasia would have on people's families and in wider society and vice versa. First, it would require an investigation on whether there would be any material or practical costs involved, for example, special healthcare needs and whether there are sufficient resources within the families, communities or at a government level to support these needs should they arise. Second, an analysis of the social costs are necessary. Social costs include thinking through the contributions those with Achondroplasia may be able to offer society such as a unique perspective on social issues and maintaining a diverse population. Furthermore, it is important to consider the social costs involved in having less diverse communities, including whether performing these kinds of edits on a broader scale runs the risk of a slippery slope towards genetic homogeneity.

Mātauranga (Wisdom Encompassing all of the Virtues)

Knowing how to exemplify the various virtues is expressed through this virtue. In the case of Huntington's, there appear to be only negative features in having this disease, but there are always risks involved in any procedure, even when performing potentially life saving gene edits. Mātauranga in this case will serve to take a balanced approach to the mātātoa that decision-makers may exercise towards performing such an edit for example, ensuring that blind confidence does not overshadow other important considerations. Although this case does not appear

highly controversial, especially when compared with Achondroplasia, mātauranga should always play a role in the decision-making process.

For Achondroplasia, decision-makers need to exercise mātauranga when accounting for the stakeholders' personal desires, one's right to bodily autonomy (of both parents and their offspring) and being appropriately concerned with the flourishing of the individual and the community in which they live. Special considerations will also need to be taken concerning upholding whakapapa and whether performing the edit causes damage to, or enhances flourishing within the family line. With the right social and health support it may be entirely feasible to have a child with Achondroplasia. However, if the societal and even the familial stressors of having a child with this condition are likely to cause harm to any offspring then mātauranga will be essential here, as multiple considerations will need to be carefully balanced in employing the other virtues relevant to the appropriate degree.

6.4 Casuist Analysis:

For Huntington's, it is difficult to imagine many strong objections to performing a germline edit, given the known negative effects of this disease as detailed in the morphology and taxonomy of the case. Huntington's puts one at a significant physical, mental, psychological and social disadvantage later in life with the prospect of premature death. Alternatively, it is impossible to ensure that a family line will not pass on the gene other than by opting out of reproduction. To recommend that a family opt out of reproducing seems harsh, particularly given that a potential treatment can be made possible through CRISPR. Having Huntington's poses a significant health risk. The parents, having ownership of and autonomy over their reproductive cells may have a say over how their cells are used. However, it is necessary to balance the parents' interests and rights against the interests and rights of their children and future generations more generally. Granted, performing this particular edit does override autonomy from the offspring with regard to their biological makeup. In this case it seems an acceptable option to go ahead with the edit as it most clearly falls within the paradigm of treating human diseases. However, even in such an example, casuistry cautions us that this cannot be a blanket approval to perform such edits. The details of individual cases may well be significant enough to warrant a different approach. In other more difficult or ambiguous cases, the issue of ownership over germ cells will hold much greater significance. In this apparently less controversial case the virtue of mātātoa would

likely mean decision-makers would find in favour of performing the edit. However, the details of each case as it arises shows the need for mātauranga in responding appropriately to the framework outlined in the steps of the casuist process.

For Achondroplasia, the parents, having ownership and autonomy of their reproductive cells may again have a say over how these cells are treated. It is unclear whether they have autonomy or decision-making powers over their potential offspring in this case. Whilst this issue was less controversial in the Huntington's case, it is much more difficult to make a decision-here. The parents have a responsibility for the wellbeing of the child but it is more difficult to determine whether performing the edit is morally right or wrong or whether it infringes on any potential offspring's right to have altered or unaltered genetics.

This case links to the philosophical debate between Transhumanism and Bioconservatism in chapter 2. It would be difficult for the Bioconservatist to claim that using CRISPR to perform such an edit is dehumanising in the case of Huntington's, especially when compared to the effects on a person who is living with the disease. However, when considering Achondroplasia, it is not as easy for the Transhumanist to claim complete victory in the debate on using technology to transcend human limitations. There are those who passionately feel that it is dehumanising to perform an edit to remove the instances of Achondroplasia, as it is seen to be removing a key part of what gives their life meaning (Cokely, 2017). These kinds of cases show the importance of understanding the underlying values at play in such circumstances. However, those claiming 'dehumanisation' through an edit should take into account the effect of any other related health, social and cultural risks to the person born with Achondroplasia as discussed previously in the 'Morphology' of the case. On this basis, the Bioconservatist would therefore have to work harder to justify the argument for dehumanisation through such an edit. The 'Taxonomy' of this case indicated that there are no other cases so far to draw comparisons from, however, there may well be cases from which to draw from in future. 'Taxonomy' is therefore important in building a detailed account of the results and contributing factors in any cases that may arise in future to aid in the 'Analysis'. Here, virtues of pono (integrity in transparency), whanaungatanga (concern for civic and community flourishing) and mātauranga (wisdom) come into play for individual cases. Decision-makers would need to determine an honest account of the parents' potential fears and abilities to manage the effects of performing or not performing the edit. There would need to be a thorough

assessment of the support services available to the potential offspring in each case, from economic to social supports both within the immediate family and their wider community. Whanaungatanga would include asking questions of whether it is favourable to have a society that shuns or favours certain lifeways over others for example. Mātauranga is essential therefore in determining the correct balance of the virtues as they apply within the framework of the case and then employ mātātoa ki te whakaiti (courage with humility) in making the decision, taking into account the known risks.

6.5 Summary from Case Studies

Working through the case, it is apparent that employing such virtues within a casuist framework does not give a cut and dried answer or specific action guidance. Whilst it may be true that this approach is not specifically action guiding, the combination of casuist methods with virtue ethics does provide a comprehensive way of illuminating various courses of action that could be taken within a practical and defined context.

I maintain that the non-action guiding aspect of virtue ethics is a positive feature and not a flaw, particularly in the area of rapidly improving and cheap gene editing. There may be some cases where there appears to be no clear 'right' choice. The crux of the argument is that there will be many ambiguities as further possibilities open up through gene editing technologies and the moral path may therefore be unclear. I do not propose the virtue ethics-casuist approach as a perfect answer to such conundrums. However, it is a useful approach to consider, particularly in the setting of individual cases, alongside calculations of utility or moral rules for illuminating a broader picture of the multiple factors at play in the face of the ethically complex challenges that CRISPR presents. Even though there may be no easy answers, a virtue ethics-casuistry approach could be an effective tool to get us closer to the answers and be in a position to accommodate the ambiguities that remain. I have demonstrated working through these cases that this approach does maintain its structure and integrity as a theory. It does expand our considerations beyond paradigms of calculations and formulas of loss and gain, life or death, happiness or unhappiness. Virtue ethics combined with casuistry serves to broaden the scope of our considerations to make a decision on specific action.

Conclusion

The ethics of gene editing is not a new debate. However, this work has shown that the advent of new gene editing technologies has increased the urgency for new approaches and decisive action on how we address it. CRISPR in particular has opened a new world of possibility, from potentially curing some cancers to enabling enhanced ways of being in the world. Importantly, CRISPR has made these possibilities much more likely to arise in the near future and become more widely available than previously anticipated. However, without careful management and well informed, virtuous decision-makers, the potential for disaster remains a distinct possibility.

This work has given an overview of the unique challenges and possibilities we face through CRISPR, canvassing global and local responses to gene editing thus far. It has shown the importance of reviewing our own response to CRISPR as New Zealanders, highlighting the urgent need for updated policy on gene editing applications.

How society forms policy is underpinned by personal and societal value systems that are based in certain philosophical belief systems. That is to say, what we value as individuals, will shape our collective attitudes and values, informing policy and laws in support of those values.

The ethics on gene editing are inherently value laden, and this work has shown the importance of investigating which values make up the basis of our decisions, those values which shape our idea of human flourishing. I have argued for a flexible, toolkit approach based on virtue ethics in combination with casuistry as a viable method of informing those who are to make decisions on such contentious cases as outlined in the final chapter. Rigid rule systems or calculations of utility will likely be swamped by an inability to accurately calculate best utility, just as deontic moral rules may lack the specificity to navigate complex and changing moral conundrums. Virtue ethics acknowledges and makes room for human emotions and biases that exist and will continue to exist in decisions that pertain to human nature and what it means to flourish. The virtue ethics toolkit espoused in this work allows for real-time flexibility, whilst maintaining a stable core of values on which to base such real-time decisions.

This project has highlighted the need for further study into the use of virtue ethics-casuist perspectives for gene editing cases going forward, particularly in light of the existing gene editing policies in Aotearoa New Zealand which have not been formally revised in more than two decades.

The virtues outlined in this work do not aim to give explicit action guidance. They allow an expansive view on the myriad of contributing factors and complexities of numerous stakeholders in such decisions. Our response to CRISPR is a matter of urgency. Further discussion is needed regarding how we navigate ourselves in a world where what was once only theoretical is now possible. Looking to the virtues in decision-making processes will allow a flexible approach to each case, whilst grounding such decisions in a common goal of flourishing, brought by the continued cultivation and practice of the essential virtues as proposed in this work.

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