Gene Editing (GE) in Aotearoa New Zealand 2024 and beyond.

ICBC 2024

Gene editing was last reviewed in Aotearoa New Zealand some 20 years ago. The current coalition government has promised to start reviewing GE legislation this year, and enact new legislation by the end of 2025. The InterChurch Bioethics Council agrees that our GE regulation needs to be reassessed due to GE technology and its scope having advanced considerably in recent years. However, we urge an emphasis on the government's full public consultation with easily accessible and understandable information about GE, so that New Zealanders can make their own informed decisions about the ethical use of gene technology in the many different contexts that are now possible.

This resource has been compiled to give the general public a brief summary of updated information on gene editing. Discussion starters are included to begin individual and group exploration of the benefits and risks that might surround the many possible and potential uses of gene editing technology today and into the future.

Contents

1. History of GE in Aotearoa New Zealand until now.

The expanding knowledge and capability of gene edited/modified/engineered organisms (GMOs) and other gene editing technologies (GE), since the 1970's, has led to considerable comment and divergent views on the current and future use of gene editing in Aotearoa New Zealand (NZ).

In May 2000, the then National government set up the Royal Commission on Genetic Modification. The Royal Commission's directive was to report on options available for using GE and to make recommendations for ongoing policies and law changes needed to deal with risks and benefits of using GE in NZ. The Royal Commission report[1] recommended that NZ cautiously keep GE options and opportunities open for both conventional and GE agriculture while protecting our 'clean green' reputation, develop a strong biotechnology strategy with public consultation, have regulatory monitoring of any GMO release or import to reduce environmental risk, and establish a NZ parliamentary commissioner for GE.

In response, the government placed a 2-year moratorium on GMO release into the environment under the watch of the Environmental Risk Management Authority (ERMA) with appropriate new legislative changes. In 2002 the government established Toi te Taiao, The Bioethics Council. In addition to providing advice to the government on biotech issues that have a cultural, ethical and/or spiritual dimension, Toi te Taiao had a considerable public education and consultancy role. In 2003, as the moratorium approached its 2-year limit, the newly formed InterChurch Bioethics Council (representing Anglican, Methodist and Presbyterian churches) compiled a study document around the current GE issues and suggested questions for discussion[2].

The government's review at the end of the moratorium resulted in the regulation of the 1996 Hazardous Substances and New Organisms Act (HSNO) continuing in general until the present day. The 2003 "New Organisms and Other Matters Bill" (NOOM), which sought to redress deficiencies in the HSNO Act, added the need for consideration of 'cultural, ethical and spiritual issues' into legislation.

In 2009, the NZ government disestablished the Toi te Taiao Bioethics Council, and in 2011 ERMA was disestablished, with GE regulation coming under the control of the Environmental Protection Authority (EPA).

Currently, release of GE organisms in NZ remains highly regulated under the HSNO Act and the EPA. This includes ensuring laboratory containment only for GMO's, with strict conditions applying to both the field release and some conditional release. Alongside agricultural and environmental sciences, GE relating to healthcare technologies was also considered, with these now being overseen by Te Whatu Ora/Ministry of Health. Assisted reproductive technologies (ART) are regulated by Ministry of Health's ACART (advisory council for assisted reproductive technologies) and its ethics council ECART, with occasional public consultations bringing public viewpoints into ACART policy decisions.

In 2017, the Royal Society of Aotearoa New Zealand (Te Aparangi) held a consultation/discussion workshop on gene editing[3] using the new gene technology CRISPR for agriculture, for conservation/pest eradication, and for healthcare. The consultation included the exploration of

[1] Royal Commission on Genetic Modification. 2001 Report of the Royal Commission on Genetic Modification | Ministry for the Environment

[2] Where do we stand? ICBC resource, 2003 ICBC website, GE topic http://www.interchurchbioethics.org.nz/wp-content/uploads/2017/03/Where-do-we-stand.pdf

[3] Gene editing in Aotearoa (royalsociety.org.nz)

medical, ethical, cultural and legal considerations for a variety of scenarios. The Royal Society expert panel later concluded[4]:

"Across all scenarios, feedback from Māori participants highlighted the importance of whakapapa and mauri, involving tangata whenua around indigenous species, protection of data, and intellectual property implications of gene editing taonga species. 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 rather than focusing on the gene-editing process itself. There is also an urgent need for a wide and well-informed discussion across New Zealand's diverse communities about their preferences for application of gene editing, in order to inform any regulatory change."

In 2022, former Green Party leader Jeanette Fitzsimmons called for a new Toi Te Taiao Bioethics Council to be re-established, in order to consult and discuss the ethics of new technologies such as synthetic biology, artificial intelligence (AI), nano-technology and geo-engineering[5].

In 2023, the then opposition National Party reported the Environmental Protection Agency had approved fewer than ten GE or GM products for release outside of laboratories under the current HSNO Act rules; that no commercial GE or GM crops were grown in New Zealand; and no fresh produce based on gene technologies were sold here. They regarded this regulation acting therefore as an "*effective ban on GE in NZ', which would be reviewed if they were in government"* [6].

Prior to the general elections in Oct 2023, science and technology spokesperson Judith Collins said the HSNO Act was out of date with the last two decades of developments in GE, particularly CRISPR, which allows precise gene editing. Collins announced a "Harnessing Biotech Plan" that would end New Zealand's effective ban on GE, create a dedicated regulator for the technology, and streamline approvals for trials and use of non-GE biotechnologies[7]. She argued there are immense economic benefits to liberalising New Zealand's GE rules, as well as benefits in health, climate change responses and other environmental issues. Prior to becoming Prime Minister in October 2023, Christopher Luxon said that the party's policy would be 'quite conservative and any risks would be incredibly well managed by the new regulator'[8]. Now in 2024, with a National-New Zealand First-Act coalition government, PM Christopher Luxon and Minister for Science and Technology Judith Collins have both announced future plans to review and change legislation for GE that will be in place by the end of 2025.[9]

Today, two bioethics groups, Te Kupenga (the Catholic Nathaniel Centre) and the InterChurch Bioethics Council (Anglican, Methodist, Presbyterian), continue to consider the bioethics of emerging and developing biotechnologies in Aotearoa NZ, including with a spiritual focus. In May 2024, an open letter was sent jointly between ICBC, Te Kupenga, NZ Christians in Science and the Christian Medical Fellowship of NZ to offer support for a review of GE legislation, with a request for

[4] Calls for overhaul of gene-technology regulations and wide public discussion (royalsociety.org.nz)
[5] Greens Called To Reinstate Toi Te Taiao -The Bioethics Council | Scoop News
[6] National promises to end Genetic Engineering ban - NZ Herald 2023
[7] Future of gene tech likely focus for National-led government | RNZ News
[8] NZ's GMO laws to be loosened under National govt - Luxon (1news.co.nz)
[9] Judith Collins promises gene-editing law changes - but they are not on the urgent list - NZIAHS (agscience.org.nz)

a program of full information and consultation with a wide variety of community groups as well as scientists and businesses.[10]

Recently, on August 10 2024, the NZ government announced that legislation to end the ban on GE and the setting up of a regulatory group to oversee future GE will start this year and be enacted by the end of 2025.[11] The government says that changes and the new regulatory body will be similar to that used in Australia by the Australian Gene Technology Regulator[12]. However, Minister Judith Collins has said on 18 Sept 2024 that ethical considerations will not be included in the Bill being put forward, or indeed any mention of having a precautionary approach, due to already formed ethics bodies such as the National Ethics Advisory Council (MoH), National Animal Ethics Committees and Health Research Ethics Boards.[13] How these bodies inform and direct a Regulator on any ethical concerns is yet to be outlined.

How important do you think cultural, ethical and spiritual considerations are in Aotearoa New Zealand for establishing use of new biotechnologies such as gene editing?

How would you like to see the government hear and act on views of the public today?

2. New Gene Editing Technology – CRISPR (gene cutting/pasting):

A new gene editing technology called CRISPR (Clustered Regularly Interspaced Short Palindromic Repeats)[14] was developed as a gene cutting tool for use in the laboratory in 2012. CRISPR gene editing is based on a modified process used naturally by bacteria to cut up and destroy any invading viral DNA (see video to explain how CRISPR works[15]). CRISPR enables DNA from human and/or other species to be specifically cut and pasted inside another living cell, animal or plant, so enabling a DNA sequence to be repaired or changed in a very precise manner. The benefits and risks of CRISPR are many and complex. How benefits and risks are considered may depend on the purpose, context and relational impact of any modification.

The beneficial uses of CRISPR worldwide are already being seen in:

a) Agriculture/primary industries - to enhance crop, livestock, and forest production more rapidly and specifically than traditional horticulture and farming methods, and that may lead to less pesticide use, and crop or stock tolerance to adverse conditions.

[10] http://www.interchurchbioethics.org.nz/wp-content/uploads/2024/04/Letter-to-Incoming-government-January-2024-re-Genetic-Modification-FINAL.pdf

[11] Ban on gene technology outside lab to end, government announces | RNZ News

[12] Office of the Gene Technology Regulator (ogtr.gov.au)

[13] www.rnz.co.nz/national/programmes/morningreport/audio/2018955860/minister-defends-proposed-ge

[14] https://www.youtube.com/watch?v=UfA_jAKV29g

[15] Royal Society Te Aparangi animated video explaining gene editing https://vimeo.com/191676165

b) Conservation of endangered species - to enhance their adaptations for hostile environments, especially in climate change, and to evade or eradicate their pests.

c) Medical Healthcare - gene therapy to repair or replace faulty, disease-causing DNA with functional, non-disease gene sequences in an individual's somatic cells that will not affect future generations, or within germ cells (eggs, sperm, embryos) which result in inheritable changes throughout future generations. Targeting gene therapy to a certain organ or somatic cell type can be difficult, and not all DNA in a person will be changed. However, often only some DNA being altered is enough to restore health to a person.

Potential risks with using CRISPR technology include:

a) Epigenetic changes: not all the effects during the lifespan of a person/animal/plant resulting from the DNA changes made by CRISPR are known as yet. By changing the linear coding of a DNA genetic sequence with CRISPR, there is also the potential of change in the use or function of other parts of the genome at some later stage. Normal epigenetic changes involve the chemical 'decorating' of DNA or of the proteins coded by the DNA or surrounding the DNA in order to regulate the DNA expression in some way (explained in this video[16]). In this way, normal epigenetic changes enable an organism's cells, all with the same DNA, to differentiate into the many cell types found within that living organism, therefore directing the natural development of that plant or animal. Abnormal epigenetic changes may cause abnormal development of the living organism, and are often caused by environmental factors and disease. Likewise, any epigenetic effects resulting from CRISPR modification of a particular DNA sequence is mostly unknown as yet, but will likely be long-lasting and may be inherited.

b) Reversible? It is also not known as yet if CRISPR changes can be fully reversed by scientists in the event of unintended consequences.

c) Consent of future generations: if gene editing via CRISPR is used for inheritable changes within people, future generations will be affected without being able to give their informed consent. Depending on the context, lack of consent may or may not be thought to be important.

d) Horizontal gene transfer is another risk of unknown proportions for gene edited organisms that are released outside a contained environment, such as a laboratory, into the natural environment. Horizontal gene transfer is the uncontrolled movement of genetic material between organisms other than by the 'vertical' transfer of DNA from parent to offspring during reproduction (explained in this video[17]). It is possible that the edited gene from a GE animal, plant, or fungus may unknowingly be transferred into the genome of bacteria/virus/fungi living inside the animal or plant, which is then excreted or secreted out into the soil and wind. The edited gene within the bacteria, fungus or virus may then be taken up into other species in the environment. In some other cases, horizontal gene transfer can occur straight from one animal species to another, or one plant species to another, without using an intermediary vector such as bacteria, virus or fungus. In nature, evolutionary tracking of living organisms shows that horizontal gene transfer is responsible for much of the natural evolutionary changes in a species' genome. However, horizontal gene transfer is also the mechanism known to have resulted in antibiotic resistance and pesticide-resistance we see today - where bacterial antibiotic or pesticide resistance genes have become incorporated into the genomes of

[16] (14) Can Your Environment Affect Your DNA? | Epigenetics Explained - YouTube
[17] I'm A Genetic Engineer. I'm Also a Fish. (youtube.com)

other bacteria/fungi/plants/animals. Therefore, any GE regulation would need to be closely monitored for horizontal gene transfer in natural environments.

e) CRISPR presents a significant risk to **soil and food sovereignty in Aotearoa New Zealand**. GMO products and technologies are developed and patented mostly by large multinational corporations. For example, in 2011, 75% of GMO seed sales (approx. USD$25billion) internationally were made by just 10 companies.[18] Some companies have effectively monopolized certain products and technologies. Once a product is patented, it can be sold. If the product performs better than non-GMO products, farmers can easily be forced to buy the patented product in order to compete. In this way, soil and food sovereignty and resilience can be eroded by the globalisation, capitalisation, and patentisation of GMO products and technology. Māori are leading the way in researching the potential risks and adverse effects of these technologies.[19]

f) Acceleration of the loss of biodiversity is a risk when CRISPR is used in monocultural farming. Loss of biodiversity is already a significant concern as native forest and shrubland is replaced with monocultures (like soy, pine etc.) As GMO seeds monopolize a market, this biodiversity loss will only be accentuated. Often GMO plants are edited to be resistant to pesticides, resulting in higher use of pesticides that damage other plants and the loss of insect biodiversity. One potential consequence is that some weeds and pests will evolve, including via horizontal gene transfer, to become resistant to pesticides and requiring the use of stronger pesticides. As in the case with antibiotics being used in factory farming, there is a risk that increased resilience of pests could create “super-pests” that could significantly disrupt food supply chains and eradicate taonga species.

g) The necessary transition to a regenerative, low-carbon, circular economy which is fundamental to addressing climate change may be slowed by the use of GE in primary industries. Often GMO products are defended as necessary in order to address food insecurity and to meet the needs of a growing human population. However, globally enough food is already produced to feed the world sufficiently. In 2023, it was revealed 100,000 tonnes of perfectly good food is wasted every year in Aotearoa New Zealand.[20] By simply increasing the productivity and emphasising economic growth through GE technologies, the underlying consumer behaviours that create the problems are not being addressed. Rapid transition to a low carbon future (at the rate required to keep warming to sustainable levels) will require moving towards a circular “degrowth” economic system and the recovery of regenerative farming techniques. GMO risks hindering that necessary transition.

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[18] https://www.foodandpower.net/gmos-seeds

[19] See the work of the Papawhakaritorito Trust: https://www.papawhakaritorito.com/
Also: https://www.teaonews.co.nz/2024/04/11/reclaiming-indigenous-seed-soil-health-and-food-sovereignty-discussed-at-symposium/

[20] https://lovefoodhatewaste.co.nz/food-waste/what-we-waste/

Possible scenario examples for GE using CRISPR technology in primary industries, for conservation and in medical care are expanded below (taken from the Royal Society of New Zealand discussion booklets for GE using CRISPR technology):

a) Gene Editing using CRISPR in Primary industries[21]:

i) GE of pines that are prone to become wilding, so they don't regenerate would benefit native flora and fauna. But at present we do not allow GMOs outside of containment in NZ.

ii) GE of fungi that deter grass pests to become tolerated by livestock feeding on the grass. It may be difficult to keep non-GE and GE fungi in plant seeds apart.

iii) GE of a fast-flowering gene into apple DNA, to reduce the time needed to test different apples. When a particular apple result has been selected, the fast-flowering gene may be edited out for the normal gene again, so the final apples are not GMO, and GE apples do not enter the general food chain.

iv) GE for disease-resistance in manuka – to strengthen manuka plants which are used in pollination for honey production. Manuka is a taonga species susceptible to myrtle-rust, so conservation could be aided. Honey might be regarded as GM, and difficult to keep GE and non-GE plants separate.

v) GE of cows to eliminate B-lactoglobulin from milk, benefitting people who cannot tolerate dairy milk with B-lactoglobulin protein. The milk and meat from these animals would be GE products, and the animals and their gametes would be GMOs.

More recent applications:

- GE could be used to speed up breeding of livestock that have lower green-house gas emissions[22]

-GE used to give faster herd adaptation to climate change conditions. However, this risks unknown effects in the stock animal, edited genes might enter the food chain and affect our export markets.

What do you think are the most important benefits of using GE in primary industries? What are the most important risks?

How could we increase benefits and deal with risks?

[21] Gene editing for the primary industries (royalsociety.org.nz)
[22] Applying technology from low-methane sheep to cattle | RNZ

b) Gene Editing using CRISPR for conservation[23]:

CRISPR gene editing could potentially be used to enhance taonga and/or endangered species to tolerate harsh conditions, or protect an endangered species against predators.

However, some applications require a further step. For example, using CRISPR for pest/predator control via editing to make the pest infertile would be slow and have limited effect as many pest species have short life cycles and gene edited members of a species would be replaced quickly by non-edited members. In such cases, a **gene drive** could be inserted alongside the edited gene which ensures the changed gene is always inherited and spreads through a pest population quickly.

What is a gene drive? (explained also in this video)[24] Gene drive technology enhances the ability to pass on a genetic trait from parent to offspring. For example, in addition to the CRISPR edited gene to render a pest's offspring infertile, as in the example above, a 'drive' DNA sequence is also added into the gene editing. In normal sexual reproduction, offspring inherit two versions of every gene, one from each parent. Each parent also carries two versions of the gene, so there is usually an equal probability that a particular variant of the gene will be passed on to offspring, and in future generations, the edited changed will be seen less and less. Gene drives, however, ensure that the genetic changes will almost always be passed on, allowing that edited variant to spread swiftly through a population over several rapid generations.

Examples of using a gene drive with CRISPR in gene editing:

i) Reducing populations of invasive wasps by inserting infertility genes under the control of a gene drive which prompts the infertile gene to be expressed rather than the natural wasp fertility gene. NZ has very high densities of wasps, which are a threat to honey bee populations. However, GE wasps could spread to other countries where they are not a pest. There is a possibility that the gene drive could be horizontally gene transferred.

ii) **Reducing fertility of the brushtail possum** by gene editing possum egg cells with an infertility gene drive – possums are our most populous pest, affecting many native flora and fauna. However, a question is whether GE possums could spread to countries where possums are valued.

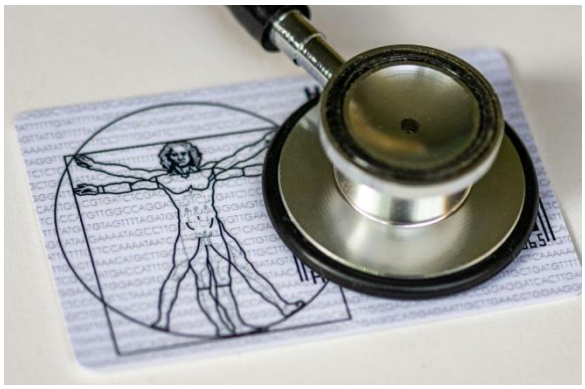
iii) GE under a gene drive to **reduce fertility in stoats and rats**. However, for some iwis, the Polynesian rat kiore is regarded as a taonga.

What do you think are the most important benefits of using GE in conservation, in pest control?

What are the largest risks – how and who should deal with these risks?

[23] Gene editing for pest control (royalsociety.org.nz)
[24] What is a Gene Drive? - YouTube

c) Gene Editing using CRISPR in healthcare[25]:



encompasses treatment of the somatic cells of one individual which would not be inherited, through to editing of an individual's germ cells (egg or sperm cells) that would be inherited down a family tree, potentially affecting many generations.

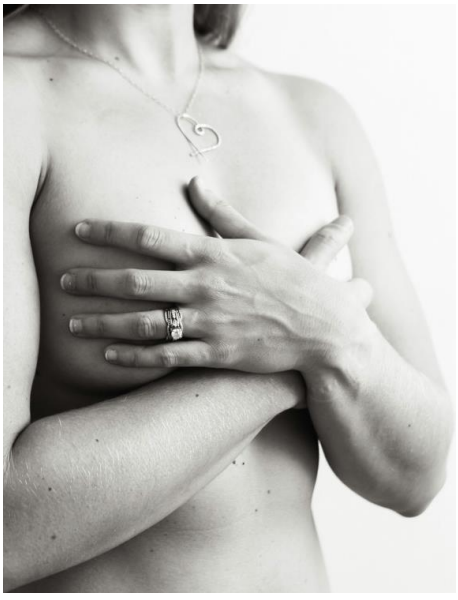
Inheritance of edited genes by future generations is problematic as any future generations have not consented to the change. The benefits may outweigh this, but there may be the risks of unintended effects from the gene editing. While scientists know the gene coding which has been changed by the editing, there are possible downstream epigenetic and other effects that are unknown as yet.

Also, an important consideration in healthcare is identifying the point at which a medical treatment becomes an enhancement, and the ethical issues of purpose that accompanies this change. (Treatments return the person to a normal state of health, enhancements take them beyond what is normal function, so identifying when this is ethical and allowable is key.)

Examples:

i) Body tissue gene therapy, such as **gene editing of bone marrow to treat sickle cell anaemia**. This helps a single individual who has the disease and who has given informed consent. This change is not inherited into future generations.

ii) Body tissue genetic treatment to **improve the cardiovascular health** in an individual with a family history of early death from coronary artery disease by improving lipid-lowering enzymes in the liver. This would be positive for the individual's health and could be economical for the country's health budget. However, the possibility of unintended effects exists here too. Further, would everyone have access to this sort of treatment?



iii) **BRCA1 breast and ovarian cancer gene editing** – to prevent a woman's children from inheriting the BRCA1 gene, she undergoes IVF and preimplantation genetic diagnosis to identify which embryos have the BRCA1 gene. The embryos without the BRCA1 gene could be implanted for pregnancies, or those embryos with the BRCA1 gene could be gene edited to correct this mutation. Both scenarios avoiding mastectomies and removal of ovaries in adult life. However, embryonic GE would alter future generations without the consent of future recipients. This might improve future lives but may have unknown unintended effects for future generations. While this could be a real benefit for affected communities, it is currently not permitted in NZ with the Human Assisted Reproductive Technologies Act 2004 prohibiting GE of embryos.

[25] Gene Editing Scenarios in Healthcare – Summary by Royal Society Te Apārangi - Issuu

iv) Embryonic genetic enhancement for erythropoietin blood levels to be increased in athlete's children. This affects future generations without their consent, and may again have unknown, unintended consequences. This would be for the purpose of enhancing beyond normal ability rather than to repair back to normal ability, so it is not regarded currently as a medical treatment. As this would not be accessible to all athletes geographically and financially, it would result in unethical advantage in sport. Could this achieve a grey area between being human and being an enhanced type of human?

How do you view GE in healthcare compared with GE in agriculture or for conservation?

What do you think would be acceptable/not acceptable for gene editing in humans?

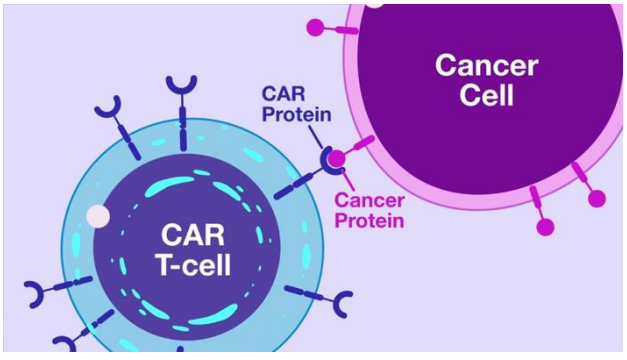
How do we remain valuing of people with disabilities, and ensure healthcare treatments are accessible to everyone (economically, culturally, geographically)?

3. New CAR T-cell therapies using CRISPR Gene Editing in somatic cells[26]:

A new biotechnology that uses CRISPR gene editing in its processing is CAR T-cell therapy (Chimeric Antigen Receptor T-cell therapy)[27] [28] [29].

CAR T-cell therapy is becoming a successful frontrunner for treatment in blood cancers internationally. In NZ, CAR T-cell therapy has been trialled for manufacture and treatment through the Malaghan Institute of Medical Research (MIMR) in Wellington.

A one-off treatment, CAR T-cell therapy works by redirecting (using CRISPR genetic editing) a patient's own immune T-cells in the laboratory, to directly identify and attack the specific cancer cells of the patient. These modified T-cells are then replaced into the patient in hospital where they can attack and destroy cancer cells much more effectively than before.



[26] NZMJ-Chimeric-antigen-receptor-T-cells-in-New-Zealand-challenges-and-opportunities-Sept-2021.pdf (leukaemia.org.nz)

CAR T-cells have the potential to act as 'living drugs', providing long-term protection against relapse, or can be edited to operate for a one-off clearance of cancer[30] [31] [32].

Currently, CAR T-cell therapy works better for blood and lymph cancers than for solid cancers. Phase 1 clinical trials at the MIMR have tested patient safety, with upcoming phase 2 trials to test for efficacy of treatment. In August 2022, the Environmental Protection Authority approved the release of gene-edited T-cells that are unique to each patient[33], and in May 2024 approved CAR T-cell treatment phase 2 trials to begin with NZ company BioOra.[34]

Ethical issues at present include Māori cultural requirements and equitable access to all patients (lowering costs and increasing locations available). CAR T-cell technology is being looked at worldwide for ability to treat other cancers and diseases, and future vulnerabilities to these (for example, for people who have BRCA1 genes but no cancer as yet).

4. Gene editing in healthcare around the World.

The historical timeline of making inherited GE changes through germline cells has been short, but dramatic. While assisted reproduction IVF started in 1978, through 2000-2005 there was an agreed scientific global ban on all studies involving cloning and gene editing of human germline cells and embryos. In 2015 scientists proposed a similar moratorium after CRISPR was first described but this time asking nations to create explicit laws or regulations to prevent such studies for now, and to develop a framework for allowing the studies when they are safe and acceptable.

Then after scientist He Jiankui reported his embryonic gene editing for immunity to HIV infection, and the subsequent birth of gene edited twins in 2018, there was a call from scientists for a global regulation to be reframed and clarified around GE of human embryos and gametes[35]. In 2020, The Centre for Science and Citizenship cited research that showed 70 of the 106 countries studied prohibit heritable human gene editing, 5 countries prohibit but have possible exceptions, and the other 31 countries don't have a clear stance on this, however no country explicitly permits it[36].

In contrast, non-inherited somatic cell gene editing in humans appears somewhat more straight forward ethically than GE in germline cells with inherited changes. The World Health Organisation WHO in 2021 provided the first global recommendations for GE as a tool in public healthcare after a broad global, 2-year consultation that included scientists, patient and faith groups, and indigenous peoples. The WHO emphasis was on safety, effectiveness and ethics of somatic, germline and heritable

[30] MMR-CAR-T-Infographic-V4-High-Res4-5-WEEKS2.jpg (3508×2253) (malaghan.org.nz)
[31] https://youtu.be/OadAW99s4Ik
[32] https://www.youtube.com/watch?v=DM5d1F9YqXI
[33] GMO blood cancer therapy gains EPA approval | EPA

[34] CAR T-cells approved by EPA for phase 2 trial (malaghan.org.nz)
[35] Experts Are Calling for a Ban on Gene Editing of Human Embryos. Here's Why They're Worried | TIME
[36] New research shows that heritable genome editing is prohibited in most countries with relevant policies | Center for Genetics and Society

human genome editing[37]. Currently, individual patient treatment is being carried out increasingly, including for sickle cell anaemia in the US[38] and for identified rare diseases and blood cancers in NZ[39].

5. New Zealanders' current ethical, cultural, spiritual attitudes towards GE.

There is likely to be a diversity of views regarding GE existing in NZ today, just as there was back in the early 2000's. Whether in healthcare, agriculture or conservation, issues including protecting organic/natural farming, being pesticide-free and clean/green; NZ's ability to develop large scale economic production; lowering green-house gas emissions; and conservation methods for at-risk taonga species, views will vary.

It is important that all sectors of the public have access to accurate information, so that misinformation and disinformation is not a distracting feature of the GE discussion. Further, it is important that research from overseas and in NZ is evaluated carefully for any risks, so that decision-makers are as informed as possible.

In considering the ethics of GE in NZ, we need to ensure that *all* human rights are maintained, being fully informed with consent and consultation always required; benefits/opportunities and possible risks weighed; risks to be spread fairly; minority groups not burdened or harmed; and access and benefit justly distributed to all, with all voices heard and taken into consideration.

Culturally, in Aotearoa New Zealand, Te Tiriti and Māori input and consultation is always required, incorporating manaakitanga (care), kaitiakitanga (guardianship), whanaungatanga (connection), tapu (sacred, restricted), mana (status), tika (what is right and good), and whakapapa (ancestral lineage). Genetic material is considered tapu. There may be a fine line between guardianship to protect a species, and over-manipulation with GE to change a taonga's gene pool. Protection of Māori data, and intellectual property implications of gene editing of taonga species should be valued. For healthcare, equity of access to people groups is important – gene therapy eg CAR T-cell therapy can be very effective for the affected person, and potentially for their genetically affected whānau.

Spiritual considerations would include:

i) Humility – as created beings, how do we best care for others without becoming creator? For example, in what cases do we have the right to use GE versus when do we have the right not to use GE, now that we have the capability?
ii) Being good stewards of our planet - keeping creation in the best condition that we can by maintaining species integrity and diversity, able to lessen and cope with climate change
iii) Care and compassion for others – including the poor, the sick and the vulnerable in places with food insecurity and climate disasters.
iv) Valuing humanness so it is not to be endangered or changed.
v) Leaving a good legacy for future generations in all the ways above.

[37] https://www.who.int/news/item/12-07-2021-who-issues-new-recommendations-on-human-genome-editing-for-the-advancement-of-public-health
[38] The first gene-editing treatment: 10 Breakthrough Technologies 2024 | MIT Technology Review
[39] 'A magic wand': World-first NZ gene-editing trial may offer cure for debilitating disorder - NZ Herald

Summary

Legislation around gene editing in New Zealand requires a timely re-evaluation. In doing this, alterations to GE policy and law should not be rushed to address solely economic, productivity and political gains, but also be aligned with the views and concerns of tangata whenua, tangata moana and tangata tiriti.

Attention to public viewpoints that are fully informed and have had enough time for consideration, discussion and then consultation with the government is of utmost importance for this review of gene editing. Evidence from other countries, while useful, needs to be evaluated alongside an innovative and protective filter for the Kiwi context. Within te Ao Māori, there is growing concern about biodiversity and sovereignty over soil, seed, and food. In solidarity, as tangata tiriti, we need to heed those concerns very clearly. In this way, the publicly-supported, best use of GE technologies will enable a flourishing future for all the people of our unique country of Aotearoa New Zealand.

- ***Do you think New Zealanders' attitudes to GE have changed in the past 20 years? Have your views changed?***

- ***What more information would you need to decide your views on GE, and how would you like to have your views heard and acted on by the government?***

- ***We encourage discussion with your family, friends, colleagues, church, and local community about GE in NZ, and your input into consultation when the Bill legislation is being processed.***

- ***We would value your feedback and viewpoints on the content and questions in this discussion paper, please send to***

bioethics@interchurchbioethics.org.nz

Images:

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Invasive Wasp image (p.9) from NZ Department of Conservation https://www.doc.govt.nz/nature/pests-and-threats/animal-pests-and-threats/wasps/

Bushtail Possum image (p. 9) from Te Ara https://teara.govt.nz/en/photograph/16880/brushtail-possum

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CAR T-cell therapy image (p.11) from John Hopkins Children's' Hospital https://www.hopkinsmedicine.org/all-childrens-hospital/services/cancer-institute/programs-and-services/car-t-cell-therapy