

Summer internship for INdigenous peoples in Genomics

University of Canterbury CHRISTCHURCH

2021

#### Karakia

Ko te Mauri ohooho, whaka ū i te mana, i te wehi, i ahu mai i ngā Kāhui o ngā Ariki! Tukua tēnei mata ohooho ki runga ki ēnei Tauira, ki ēnei Taura, ki ēnei Tama, ngā rerenga o Tū! He whatinga Toka Tapu, he Whāriki raranga a Io, Io Matuanui, te matawhaiapu, te mata āwhio, i ahu mai i te mana āwhiowhio, te arawhata ki te Toi o ngā Rangi, ki te koopu ora o Taane! Tākina mai te Mauri i te hūhā o Hine-te-reremanu, kia puta ki te Wheiao ki te Ao Mārama! Ūhi! Wēro! Tau mai te Mauri! Haumi ee! Hui ee! Tāiki ee!!

(Na Waka Vercoe from Ngāti Awa: This karakia whakamaunu waka refers to the joining of the spirits of the people with the spirit of the waka and that of the kaupapa)

#### He mihi

Tuia ko te Rangi e tu nei Tuia ko te Papa e takoto nei Tuia ko te here tangata Ka rongo te pō Ka rongo te ao Tihei mauri ora

Tuatahi ka huri ra ngā mihi ki a Io te pūkenga, Io te wānanga, Io Matua Kore. Tuarua ki ngā tini aitua o tēnā iwi, o tēnā iwi puta noa i te motu. Haere koutou ki te huinga o te kahurangi.

Tuatoru ki ngā whatu mōrehu o rātou mā, ki ngā mana, ki ngā ihi, ki ngā wehi, nei ra te mihi maioha ki a koutou i ngakau nui ki tenei kaupapa. He mihi hoki ki te Te Kunenga ki Pūrehuroa me te Rangahau Ahumara Kai. Na ratou i whakaae kia tu tenei wananga whakahikohiko hinengaro.

No reira, tēnā koutou, tēnā koutou, tēnā koutou katoa.

#### SING AOTEAROA 2021

Welcome to the SING Aotearoa internship programme. The **S**ummer Internship for **IN**digenous **G**enomics is a key capacity building initiative funded by Genomics Aotearoa.

In recent years there has been significant advances in the fields of genetics and genomics and an increasing focus on Māori populations and indigenous species. All research conducted in Aotearoa New Zealand should involve consultation with Iwi Māori. Thus it is important that we understand enough about the technical, ethical and cultural issues to engage researchers in robust discussions during that process.

The SING Aotearoa programme is designed to develop your understanding of genomics alongside some of the best researchers in New Zealand. We are grateful that researchers have made space to spend time with us and share their knowledge and experience. Make use of this time by asking lots of questions.

The SING Aotearoa workshop is a week-long internship, modelled on an existing SING-USA programme (<u>http://conferences.igb.illinois.edu/sing/home</u>).

The University of Canterbury, Otago Medical School, Lincoln University and Plant & Food Research are our hosts for 2021.

While genetics has been a lightning rod for debate in past years we hope that this workshop provides a space to share ideas and thoughts in an informative way.

Mā te mōhio ka mārama, Mā te mārama ka mātau, Mā te mātau ka ora. Through awareness comes understanding, through understanding comes knowledge, through knowledge comes wellbeing. Kia ora koutou katoa.

SING Aotearoa Conveners Maui Hudson Phillip Wilcox Kimiora Henare

#### Venues

#### **Rehua Marae** Address: 79 Springfield Road, St Albans, Christchurch

#### University of Canterbury

Address: 2 Dovedale Avenue, Ilam, Christchurch

#### Lincoln University

Address: Ellesmere Junction Road/Springs Road, Lincoln

#### **Otago Medical School**

Address: 2 Riccarton Avenue, Christchurch

#### Accommodation

Participants requiring accommodation will be staying at

University of Canterbury Sonoda Student Village 2 Dovedale Avenue, Ilam, Christchurch 0508 864 425 press option 1

Sonoda check-in opens from 12.30pm to 5.30pm on Sunday.

Map of village:



- Highlighted is Hinoki where meals will be served.
- Check in is in Keyaki.
- Other buildings to note are Ume and Totara where participants will be staying.

Street Address is 2 Dovedale Avenue, located on the University of Canterbury Dovedale campus. Enter the site from Dovedale Avenue and turn left. Follow the road until you see a carpark and apartments on the left. Turn left into the carpark. Any issues call 0508 864 425 press option 1.

# Programme

5:00 – 5:45 pm	Check into rooms - <u>Sonoda</u>	
6:00 – 8:00 pm	Welcome/reception dinner at accommodation	
	Reception dinner	
	- Welcome	
	- Housekeeping	
	- Whanaungatanga	
	- Faculty introductions	
	- Alumni introductions	
	- Pre-workshop assessment	
	- Prepare for Day 1: Rehua Marae	

# Sunday, 24 January 2021

# Monday, 25 January 2021 (Rehua Marae) – Conservation

7:30 – 8:30 am	Breakfast (accommodation)			
8:45 – 9:15 am	Travel to Rehua Marae			
9:30 – 10:00 am	Pōwhiri			
10:00 – 10:30 am	Mana whenua kōrero			
	Break – 15 min			
11:00 - 11:30 am	Kai Tahu Whakapapa Arapata Reuben			
11:30 – 12:00 pm	Introduction to Genetics and Genomics Phil Wilcox			
12:00 - 12:30 pm	Nohonga Kaitiaki	Maui Hudson (Zoom)		
Lunch (1 hour)				
1:30 – 2:15 pm	Kai Tahu Responses:	Levi Collier-Robinson		
	Genomics of our taonga species			
2.15 – 3.00 pm	Kai Tahu Responses:	Karaitiana Taiuru		
	Te Rūnaka o Koukourarata: Genetics			
	Position/Discussion Paper; He pou rāhui			
	mātai iraka.			
Break – 15 min				
3:30 - 4:00 pm	Cultural Foundations - CELSI	Moe Milne		
4:00 - 5:00 pm	Wānanga Time	Facilitator: Moe Milne		
5:00 – 5:15 pm	:00 – 5:15 pm Participant evaluations of the day			
6:00 – 7:00 pm	Dinner at Marae			

# Tuesday, 26 January 2021 – Gene-editing / Primary Sector (Lincoln University)

7:30 – 8:30 am	Breakfast (accommodation)		
9:00 – 10:00 am	Travel		
10:00 – 10:30 am	Mihi whakatau		
10:30 – 11:00 pm	Introduction to Breeding and Breeding Dr Phil Wilcox		
	Technologies		
	Break – 15 min		
11:00 – 12:00 pm	Breeding and Genomics in Annual Crops	Dr Samantha Baldwin	
	Genomics and population genetics of		
	Mānuka and Rewarewa	Dr David Chagne	
	New breeding technologies for fruit trees		
		Prof Andrew Allen	
	Lunch		
1:00 – 1.30 pm	Genomics in a commercial context with	Manu Caddie	
	taonga and non-taonga species		
1.30 - 2.00 pm	Maori perceptions of Gene-editing	Associate Professor Sandy	
		Morrison	
2.00 – 3.30 pm	Scenario: Class exercise	Phil Wilcox + Sandy	
		Morrison (Facilitators)	
Break – 15 min			
4:00 – 5:00 pm	Scenario: Reporting back	Drs Phil Wilcox + Sandy	
		Morrison (Facilitators)	
5:00 – 5:15 pm	Participant evaluations of the day		
6:30 – 7:30 pm	Dinner at Accommodation		

# Wednesday, 27 January 2021 – Health – (University of Otago)

7:00 – 8:00 am	Breakfast (accommodation)			
8:15 - 8:30 am	Travel to University of Otago, Christchurch Campus			
8:30 – 9:00 am	Mihi Whakatau Rangihau Te Moana			
9:00 – 10:30 am	Māori Health Advancement	Prof Suzanne Pitama		
	Guidelines and the CONSIDER			
	statement			
		Dr Phil Wilcox		
	In the absence of Strong oversight!			
10:30 am	Morning Tea – 15 min			
11:00 – 1:00 pm	Genetics and Epigenetics in MENZACs	Prof Vicky Cameron		
	Māori Governance in MENZACs			
		Dr Anna Rolleston		
1:00 – 1:30 pm	Lunch – 30 min			
1:30 – 2:00 pm	Patient/Whānau Experience	Irene Kereama Royal		
2:00 – 3:00 pm	Māori Governance workshop	Dr Anna Rolleston &		
		(Kimiora Henare)		

Afternoon Tea – 15 min		
3:30 – 5:00 pm	Māori Governance workshop	
5:00 – 5:15 pm	Participant evaluations of the day	
5:15 – 5:30 pm	Poroporoaki and return to Accommodation	
6:00 pm	Dinner at Accommodation	

# Thursday, 28 January – Wet/Dry Lab – COVID19 – University of

7:30 – 8:30 am	Breakfast		
9:00 – 12:00 pm	DNA Extraction lab - Strawberry Hands on		
	Gel loading	Demo	
	Genotyping (Sexing Birds)	West Building	
12:00 – 1:30 pm	Lunch		
1:30 – 3:30 pm	COVID19 Genomics & Bioinformatics Lab Drs Joep de Ligt & Jemma		
	Geoghegan - Rehua building		
Break – 30 min			
3:30 – 5:00 pm	COVID19 Genomics & Bioinformatics Lab	Drs Joep de Ligt & Jemma	
		Geoghegan - Rehua building	
5:30 – 5:45 pm	Participant evaluations of the day		
7:00 pm - late	Dinner at Resta		

# Friday, 29 January - Whakarāpopototanga – University of Canterbury

7:30 – 8:30 am	Breakfast	
9:00 – 11:00 am	<ul> <li>Where to from here?</li> <li>Career and Study Pathways</li> <li>Community Pathways</li> <li>Reflections from past SING- Alumni</li> </ul>	
11.00 – 12.30pm	Final workshop evaluation and poroporoāki	
Lunch		
2 pm	Participants return to airport	

#### **INTERNS for SING Aotearoa 2021**

- Tanisha Nathan
- ✤ Violet Walker
- Connor O'Sullivan
- ✤ Daniel Harrison
- ✤ Sommah Tauwhare
- Donna-Marie Warren
- ✤ Nicole Haerewa
- Victoria Hawkins
- Mikayla Apiti
- ✤ Katie-Lee Riddle
- ✤ Danielle Kirby
- Cherokee Walters
- Jordan Lima
- Morgan Jones
- ✤ Lia Heremia
- ✤ Jack Dakin

#### **SPEAKERS**

# Conservation Day - Monday 25th January

#### Karaitiana Taiuru



**Karaitiana Taiuru** has primary affiliations to Kāi Tahu, Ngāti Kahungunu, Ngāti Toa and is of Scottish descent. Karaitiana recently completed writing a PhD focusing on traditional Indigenous knowledge and effective cultural engagement processes with biotechnologies, in particular genetic and genomic research.

#### Moe Milne ONZM



Mrs Milne has been involved in addressing mental health issues in the Māori community in her roles as a psychopaedic nurse and as a general and psychiatric nurse. She has contributed to Te Hau Marire, the national Māori addiction strategy and developed several education programmes. She was a member of the Health Research Council, and she chaired the Māori health research group that developed Te Ara Tika to improve research ethics with Māori. She is part of the International Network of Indigenous Health Knowledge and Development and has spoken at conferences in New Zealand and overseas. Mrs Milne develops and delivers training in cultural competency within health services and is a member of the Māori committee of the Royal Australia and New Zealand College of Psychiatrists.

# Primary Industries Day - Tuesday 26th January

# Dr David Chagné



David Chagné was born and went to university in the Southwest of France. He identifies himself as a Gascon. David has been at Plant & Food Research since 2004 and since 2017 he is Science Group Leader for Molecular & Digital Breeding. David's research focuses on the application of genetic mapping and genomics to elucidate the genetic control of important plant characteristics, with a strong underpinning interest in the study of DNA variations in plant genomes, including taonga species such as mānuka.

David has catalogued single nucleotide polymorphisms (SNPs) in the apple, pear, kiwifruit and mānuka genomes and identified markers linked to

significant traits, including fruit antioxidant content, red flesh and peel, crispness and aroma. He designed a SNP assay that has been used to accurately predict fruit quality of young apple seedlings using genome-wide selection, years before they first set fruit.

David is a science leader in Genomics Aotearoa and is involved in several projects involving Māori, including understanding mānuka genome diversity and functioning with the honey industry, sequencing genomes of taonga species for primary production and conservation purposes, understanding Māori views to new breeding technologies, developing biocultural labels and training young Māori researchers.

#### Professor Andrew Allan



Andrew Allan has been a plant researcher for 30 years, studying the physiology, cell biology, and genetic makeup of crop plants. Much of his research focuses on new apple and kiwifruit varieties, understanding how the plants will behave, for instance in different environments or with different horticultural practices. He is currently focussed on plant response to climate change, with recent projects on

transcriptional regulation of flowering, and compounds that make fruit colourful and healthy. Professor Allan, an expert in plant molecular physiology, was the Director of the Joint Graduate School in Plant and Food Science, which was established by The University of Auckland and Plant & Food Research between 2013 and 2018. The Graduate School seeks to coordinate postgraduate teaching and research between UOA and PFR.

## Associate Professor Sandy Morrison



Faculty of Māori and Indigenous Studies, University of Waikato.

Tēnā koutou katoa. Nō Ngāti Whakaue, Maniapoto me Te Tau Ihu o te Waka a Māui ahau. Tīhei mauri ora.

Sandy's research and professional specialty focuses on adult education, education for sustainability and the application of indigenous models in addressing developmental issues to improve livelihoods for indigenous peoples and peoples of the Pacific. Sandy is the Vision Mātauranga (VM) project leader for the Deep South Challenge: Changing with our Climate. She works with the

Challenge Leadership Team to ensure that the VM perspective is strong and present at every level within the Challenge. Sandy is the President of ICAE, International Council for Adult Education, a global NGO which advocates for the right of adults to education and lifelong learning. She was inducted into the International Adult and Community Education Hall of Fame by the University of Oklahoma in 2009.

#### Manu Caddie



Manu Caddie (Ngāti Pūkenga, Ngāti Hauā, Ngāti Whare) is one of New Zealand's most trusted authorities on medicinal cannabis. Manu has 20 years' experience in research, public policy and project management, including with the World Bank and as an elected representative. He has recruited a team of plant science and medicine manufacturing specialists to establish Rua Bioscience as a plant-derived pharmaceuticals company with global reach.

#### Dr Samantha Baldwin



Samantha is the Science Group Leader overseeing the breeding of Annual Crops at PFR, including the strategy for application and implementation of genomics in breeding. Samantha started at Plant & Food Research in 2001 and completed her PhD in 2008 (UofO) with the potato breeding programme, developing techniques for identifying regions of the polyploid potato genome associated with key traits. Specifically, Samantha used both genetic linkage and genome wide association mapping to design markers for markerassisted selection and has successfully deployed these techniques,

beyond potatoes, into other vegetable and fruit crops. More recently, Samantha has been developing capture-based resequencing panels to allow sequenced-based genotyping in complex polyploids, and exploring the role of epigenetics in priming plants for new climates.

Samantha is also Direction co-leader for Horticulture Goes Urban, a new area of research for PFR undertaking basic targeted research to develop plants and production systems that will allow fresh fruit and vegetables to be grown in controlled environments within cities. Samantha is passionate about supporting co-innovation and huatahi partnerships with Māori in both of her leadership roles.

# Health Day - Wednesday 27th January

### Rangihau Te Moana



Rangihau Te Moana (Tūhoe), Pouako o te reo Māori me ōngatikanga.

Kaumātua – Tūhoe ki Waitaha, Te Whareroimata, Comm. Centre, Te Kura Kaupapa Māori o Te Whānau Tahi. University of Otago Christchurch.

#### Professor Suzanne Pitama



**Professor Suzanne Pitama** (Ngāti Kahungunu) PhD (Otago) PGDipEdPsych (Massey), MA (First Class Hons) (Auckland). Suzanne is the Associate Dean Māori at the University of Otago, Christchurch campus., and Co-Director of a University of Otago Research theme: Te Poutama Ara Rau. She is a registered educational psychologist and has been involved in Māori health research and health education for 20 years. Suzanne is focused on addressing Māori health inequities through medical education, health research and membership on appropriate committees and boards. These include the Health Research Council of New Zealand Board and as a Director on the Australia Medical Council Ltd. Suzanne has received a number of awards for her teaching including the Prime Minister's Supreme Award for tertiary teaching excellence and the Indigenous

Leadership Award from the Leaders in Indigenous Medical Education (Australasian) community of practice. Suzanne was awarded the Joan Metge Medal for her research within the field of Indigenous medical education.

# Professor Vicky Cameron



**Vicky Cameron** is a Research Professor and Deputy Dean at the University of Otago, Christchurch, where she leads the Molecular Biology and Genetics research within the Christchurch Heart Institute. Her research interests spans a broad portfolio, from fundamental labbased genomic research into the inherited origins of heart disease, to community cohorts and nation-wide studies leading to a greater understanding of the risk factors for heart disease in Māori and Pasifika communities. Her laboratory investigates genetics, and recently non-coding RNAs, for their association with coronary heart disease susceptibility and utility as blood biomarkers. More recently she has been working in the field of epigenetics, studying DNA methylation, a sensitive and specific marker of past and present environmental exposures including smoking, nutrition and social stress. Her team is studying gene-environment effects on cardio-

metabolic health in Pacific peoples living in Christchurch. The team is also investigating DNA methylation in patients with coronary disease within the MENZACS study, to determine if DNA methylation patterns predict an individual's risk of incurring a secondary cardiovascular event.

## Dr Anna Rolleston



**Anna Rolleston** (Ngāti Ranginui, Ngāi Te Rangi) is founder and director of Manawaora/The Centre for Health, which provides kaupapa Māori approaches for the management of long term conditions. In addition she holds an Honorary academic role within the Department of Medicine at Auckland University, is the co-director of the recently established Healthy Hearts for Aotearoa NZ Centre of Research Excellence and sits on a number of governance boards that span the spectrum of health from genomics through to community hauora.

### Irene Kereama Royal



**Irene Kereama-Royal,** PhD Candidate, LLM Masters of Māori, Pacific and Indigenous Rights Law. (1st Class Honours), is of Ngāpuhi and Parehauraki descent. Irene is a Kaupapa Māori Researcher at the Ngā Wai a Te Tūī Māori and Indigenous Research Centre at Unitec in Auckland and also works as a research consultant. Irene's research interests include improving Māori health outcomes, in particular with advocating ethical and cultural considerations in genomics research as well as improving access for Māori to early diagnostics and precision treatments for familial diseases, particularly cancers.

Irene is a member of the executive committee of Breast

Cancer Aotearoa Coalition, a patient advocacy network of breast cancer NGO's for better access to medicines, treatments and clinical trials. She sits on a number of Māori advisory groups for genomics research programs including the Rakeiora program at the University of Auckland and the Variome Project with Genomics Aotearoa.

# Wet Lab/Dry Lab Day - Thursday 28th January

## Dr Jemma Geoghegan



Jemma is a Senior Lecturer at the University of Otago and an associate scientist at ESR. She is an evolutionary biologist and virologist with a strong research focus on emerging infectious disease. Her research focuses on determining the fundamental patterns and processes of viral evolution, ecology and emergence. Jemma has expertise in using metagenomics to reveal the diversity, structure and evolution of the virosphere; examining the evolution of major viral infections, including SARS-CoV-2; and developing new analytical and computational approaches to analyse aspects of virus evolution. Jemma has recently been awarded a Rutherford Discovery Fellowship to better understand the virosphere in Aotearoa.

# Dr Joep de Ligt



Joep de Ligt is the Lead Bioinformatics at ESR, New Zealand, covering a wide range of organisms and genomic technologies. He has a long track record in the analysis of sequencing data in both a diagnostic and research setting. Within ESR strategic investments have been made to increase sequencing and bioinformatics capability. The genomics team he leads has a strong international network and had the ARTIC protocol for sequencing SARS-CoV-2 implemented and ready for the first New Zealand case of COVID-19. This work has subsequently demonstrated the capability and value of real-time whole genome sequencing to assist surveillance. The current research of de Ligt focuses on delivering positive health impacts across Aotearoa through genomic technologies.

# Convenors

## Dr Phillip Wilcox



**Dr Wilcox** is a Senior Lecturer in the University of Otago's Department of Mathematics and Statistics, and has experience in applied genomics and statistical genetics. He is the current convenor of MapNet a NZ-wide collective of gene mapping scientists and the Project Leader of the Virtual Institute for Statistical Genetics (www.visg.co.nz). Dr Wilcox also established Te Aroturuki, a group of Māori scientists and advisors who developed a process to assist Western research scientists engage with Māori communities. He was also part of the roopu who developed Te Mata Ira, He Tangata Kei Tua and Te Nohonga Kaitiaki guidelines. He is formally a Kaihautu Māori in both the Biological Heritage National Science Challenge and the BioProtection Research CoRE, and was a mandated spokesman for Ngāti Rakaipaaka regarding the Rakaipaaka Health and

Ancestry Study. He has worked on genetics of plant species (particularly forest trees) and human diseases. He has also led development of Māori content in genetics, agriculture, biochemistry and statistics courses at the University of Otago, as well developing genetics learning modules for pre-NCEA level 1 tauria Māori.

#### Dr Kimiora Henare



Dr Kimiora Henare (Te Aupōuri, Te Rarawa), is an early career researcher and cancer biologist, specialising mainly on the tumour microenvironment and tumour immunology based at the University of Auckland. His primary research focuses on strategies to enhance tumour-directed immunity. Alongside his lab-based biomedical research, Kimiora worked with the NETwork! Project (www.network.ac.nz) to develop a roadmap for Māori engagement for clinical cancer genomics which has served as a scaffold for several other cancer genomics projects have since been built off that scaffold where he remains actively involved as part of a cancer genomics research team led by Professor Cristin Print. In addition to his biomedical

research expertise, Kimiora teaches and advises on Responsiveness to Māori and ethics for the Faculty of Medical and Health Sciences (FMHS), University of Auckland, holds advisory and governance roles for clinical genomics research at the University of Auckland and serves as a board member of Hei Āhuru Mōwai (Māori Cancer Leadership Aotearoa). Kimiora has been involved in SING-Aotearoa since its inception in 2016.

#### Levi Collier-Robinson



Levi Collier-Robinson descends from Ngāi Tahu, Ngāti Apa ki te rā tō, Te Whānau-ā-Apanui and Ngāti Porou. He was born in Rotorua where he grew up immersed in Te Ao Māori. A product of kōhanga reo and kura kaupapa Māori, Levi is a PhD student at the University of Canterbury investigating adaptive variation in kōwaro/Canterbury mudfish, seeking to integrate mātauranga Māori (indigenous knowledge) with western science to develop a culturally-responsive, evidence-based position statement regarding the benefits and risks of prioritising adaptive potential to build resilience in threatened taonga species, including mahinga kai species destined for customary or commercial harvest.

## Ben Te Aika



Benjamin Iwikau Te Aika: Ngati Mutunga, Ngāti Tama, Te Ati Awa, Kati Wairaki, Kati Mamoe, Waitaha. Passions are my children, hunting and fishing, whakapapa and whenua. Specialist fields of Mātauraka Māori, Māori economic development. A very strong background in Māori environmental advocacy and planning analysis. I have significant experience in Māori land management. A Māori artisan, carver, taa moko.

## Associate Professor Maui Hudson



Associate Professor Maui Hudson is Whakatōhea, Ngā Ruahine and Te Māhurehure. He is Director of Te Kotahi Research Institute at the University of Waikato, focusing on the application of mātauranga Māori to decision-making across a range of contemporary contexts from new technologies to health, the environment to innovation. Maui supports Māori to engage in the research sector and advocates for Indigenous rights and interests through Te Mana Raraunga: Māori Data Sovereignty Network, the Global Indigenous Data Alliance (GIDA), and the Summer Internship for Indigenous Genomics Aotearoa (SING Aotearoa). He leads projects developing Guidelines on Genomic Research with Taonga Species, Māori perspectives on Gene Editing, and the Biocultural Labels Initiative.

#### Tuti Nikora



Ko Taupiri te maunga. Ko Waikato te awa. Ko Tainui te iwi. Ko Maniapoto te tangata. Ko Ngāti Rora te hapū. Ko Tuti Nikora tōku ingoa. He uri ano ahau no Taranaki me Ngāti Hikairo.

Tuti is the Office Manager of Te Kotahi Research Insitute at the University of Waikato.

## **Contact Information**

#### Programme conveners

Maui Hudson	027 206 1183
Phil Wilcox	021 387 892
Tuti Nikora	027 725 8139

### Links to Reading Materials – SING2021

#### **Genomes and Genomics – some basics:**

1. What is a genome? <u>https://www.royalsociety.org.nz/what-we-do/our-expert-advice/all-expert-advice-papers/gene-editing-technologies/what-is-a-genome-2/</u>

2. Sequencing technologies overview:

https://www.youtube.com/watch?v=mI0Fo9kaWqo&ab\_channel=iBiologyTechniques& fbclid=IwAR1qrMVfRE\_PkB-h7j9GYYT0l9kSFfptLQN9b8YqQi\_gNGgWcvSUYEPrcJ8

3. "Unnatural Selection" on Netflix – season 1, episode 3 – Changing an Entire Species

#### **Genomics of Taonga Species**

1. Te Nohonga Kaitiaki - Guidelines for Genomic Research on Taonga Species <u>https://drive.google.com/file/d/1ZVfN\_bWL2v1sHpMYDq6kMgVda4e7Gk8s/view?</u> <u>usp=sharing</u>

#### **Gene Editing**

1. Gene Editing – some basics: <u>https://www.royalsociety.org.nz/what-we-do/our-expert-advice/all-expert-advice-papers/gene-editing-technologies/</u>

2. Gene editing described i roto i te reo Māori: https://www.royalsociety.org.nz/assets/documents/Gene-editing-infographicmaori.pdf

3. Maori perceptions of gene editing: <u>https://www.frontiersin.org/articles/10.3389/fbioe.2019.00070/full</u>

4. Gene drives: 'Islands as Laboratories: Indigenous Knowledge and Gene Drives in the Pacific' by Riley Taitanfong – see <a href="https://bioone.org/journalArticle/Download?fullDOI=10.13110%2Fhumanbiology.91">https://bioone.org/journalArticle/Download?fullDOI=10.13110%2Fhumanbiology.91</a>. 3.01

#### **Health Day**

1. Keolu Fox's paper: - https://www.nejm.org/doi/full/10.1056/NEJMp1915987

#### Frameworks and Guidelines

Year	Framework/Publication	Whakapapa	Mauri	Kaitiakitanga	Mana
1998	Koru of Māori ethics <sup>1</sup>	•	•	•	•
2004	Te pā harakeke o te tangata²	•	•		•
2005	The obfuscation of tikanga in the GM debate <sup>3</sup>	•	•	•	
2005	Walking backwards into the future: Māori views on genetically modified organisms <sup>4</sup>	•	•		•
2006	Establishing a Māori Ethical Framework for Genetic Research with Māori <sup>5</sup>				•
2007	Biotechnology: the language of multiple views in Maori communities <sup>6</sup>	•	•	•	
2008	Te Arotūruki <sup>7</sup>	•	•		•
2011	Wai262 <sup>8</sup>	•	•	•	
2016	Incorporating Māori perspectives into decision-making protocol (EPA)		•	•	•
2016	He Tangata Kei Tua <sup>9</sup>	•	•	•	•
2016	Te Mata Ira <sup>10</sup>	•	•	•	•
2017	Tikanga Māori <sup>11</sup>	•	•		

<sup>&</sup>lt;sup>1</sup> Henare, M. (1998) 'Te tangata, te taonga, te hau: Maori Concepts of Property'. Paper presented to the Conference on Property and the Constitution, Wellington for the Laws and Institutions in a Bicultural Society Research Project, Waikato University, 18 July 1998.

<sup>&</sup>lt;sup>2</sup> Bioethics Council. 2004. Reflections on the Use of Human Genes in Other Organisms: Ethical, spiritual and cultural dimensions. Wellington: Bioethics Council.

<sup>&</sup>lt;sup>3</sup> Hutchings, Jessica and Paul Reynolds. (2005). *The Obfuscation of Tikanga in the GM Debate*. Available from www.kaupapamaori.com.

<sup>&</sup>lt;sup>4</sup> Roberts, R.M. (2005). Walking backwards into the future: Māori views on genetically modified organisms. Perspectives on Indigenous Knowledge, WINHEC Journal.

<sup>&</sup>lt;sup>5</sup> Tipene-Matua, B. and B. Wakefield (2007). Establishing a Māori Ethical Framework for Genetic Reserach with Māori. Society and the Future: Human Genome Research Project. Dunedin, University of Otago: 379-422.

<sup>&</sup>lt;sup>6</sup> Te Momo, F. (2007). Biotechnology: The language of multiple views in Maori communities. *Biotechnology Journal*, 2 (9), 1179-83.

<sup>&</sup>lt;sup>7</sup> Wilcox, P.L., Charity, J.A., Moke-Delaney, P., Roberts, M.R., Tauwhare, S., Tipene-Matua, B., Kereama-Royal, I. (2008). A values-based framework for cross-cultural dialogue between scientists and Māori. Journal of the Royal Society of New Zealand. 38(3) p215-227.

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# Guidelines for Genetic Research with Māori

Guideline	Description	Link	
Guidelines for Researchers on Health Research Involving Māori	These guidelines were developed to assist researchers in establishing research practices which ensure that the research outcomes further the improvement of Māori health and wellbeing while the research process maintains or enhances mana Māori	<u>https://gateway.hrc.govt.nz/fund</u> <u>ing/downloads/Guidelines for re</u> <u>searchers on health research inv</u> <u>olving Māori.pdf</u>	
Te Ara Tika	'Outlines a framework for addressing Māori ethical issues within the context of decision-making by ethics committee members. It draws on a foundation of tikanga Māori (Māori protocols and practices) and will be useful for researchers, ethics committee members and those who engage in consultation or advice about Māori ethical issues from a local, regional, national, and/or	http://www.hrc.govt.nz/news- and- publications/publications/te-ara- tika-guidelines-m%C4%81ori- research-ethics-framework- researcher	
Te Arotūruki	international perspective.' Developed by a team of Māori researchers and community members in response to GE challenges. A multistep process to ensure effective engagement and maximise potential for	<u>http://www.dabhand.co.nz/tap/i</u> <u>ndex.html</u>	
Te Mata Ira	Developed primarily for application in medical genomics area. Cultural framework and logic based on experiences of Māori communities.	https://www.waikato.ac.nz/ dat a/assets/pdf file/0018/321534/ Te-Mata-Ira-Genome-Research- Guidelines.pdf	
He Tāngata Kei Tua	Framework developed for biobanking/tissue banking	https://www.waikato.ac.nz/ dat a/assets/pdf file/0019/321535/ He-Tangata-Kei-Tua-Biobanking- Guidelines.pdf	
ЕРА	Resources developed to support HSNO-required consultation processes	<u>https://www.epa.govt.nz/applica</u> <u>tions-and-permits/engaging-</u> <u>with-maori/</u>	

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