

**Te Nohonga Kaitiaki**Guidelines for Genomic
Research on Taonga Species





Front Cover Image: Leaf cross-section of Harakeke (New Zealand Flax) *Phormium tenax* 

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# Te Nohonga Kaitiaki Guidelines for Genomic Research on Taonga Species

### September 2021

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# **Acknowledgements**

Te Nohonga Kaitiaki refers to the role of kaitiaki and mana whenua in managing Māori interests in biological samples or genetic resources, and data relating to taonga species across the full spectrum of activities from sample collection to sample storage, from data curation to data sharing.

Genetic and genomic research on taonga species occurs for a variety of reasons supporting conservation efforts and contributing to breeding programmes. Kaitiaki need to be involved in decisions about future uses of the information and data generated from any of these projects to ensure mana whenua and/or Māori have the opportunity to benefit from the value created.

In preparing this document, Te Nohonga Kaitiaki research team wish to acknowledge the participants, stakeholders and mana whenua who contributed to the project and these guidelines.

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# Glossary

Hapū Subtribe

Hui Meeting, gathering

Iwi Tribe

Kaitiaki Guardian, steward, caretaker

Kaitiakitanga Guardianship, stewardship, caretakership

Kanohi ki Face-to-face, in person

te kanohi

Karakia Prayer, invocation

**Kaupapa** Subject, topic, policy, matter for discussion,

plan, purpose

Kawa Protocol

Mana Authority, prestige, pride

Mana whenua General authority exercised by an iwi, hapū

or individual over a particular area of land

Manaakitanga Support, hospitality, generosity

Mātauranga Knowledge, wisdom

Mātauranga hou New knowledge

Mauri Life force, life essence

Ngā taonga katoa All treasured things

Noa Common, referring to a state of being that is

not sacred

**Pūtahitanga** Convergence, junction

**Pūtaiao** Science

Raraunga Data

Rohe Geographical area

**Taketake** Indigenous, native, original

Takiwā District, territory, region

Tangata whenua People of the land

Anything of value, treasures Taonga

Tapu Sacred, referring to a state of being that is sacred

or restricted

Te Ao Māori The Māori worldview or paradigm

Tika Correct, true, just

The customary system of values and practices Tikanga

developed over time

Tino rangatiratanga Sovereignty, self-determination, autonomy

Tuakana-teina Literal meaning: elder and younger sibling. Used

> in reference to a relationship where one party is older, more knowledgeable and more experienced than the other. What is implied is a mentor-

mentee relationship.

Wai Water

Sacred site(s) Wāhi tapu

Spirit Wairua

Thought(s), idea(s) Whakaaro

Whakapapa Ancestry, genealogy, heritage

Whakawhānaungatanga Relationship-building

Whānau Family

Whānaungatanga Kinship, relationship, connection Tui



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# **Executive Summary**

The Te Nohonga Kaitiaki guidelines apply to genomic research involving taonga species. Despite Te Tiriti o Waitangi affirming Māori rights over taonga, the application of these rights to biological samples and data has generally been overlooked within the sciences. The ease of access to genomic technologies has resulted in widespread proliferation of research, and increasing access for the scientific community as well as tertiary and secondary educational institutions. To date there has been little guidance in place to ensure that taonga species are being approached in a manner that upholds Treaty principles, or specific guidance on how this can be done effectively.

The Waitangi Tribunal has strongly recommended the protection of kaitiaki interests over taonga. International instruments such as The United Nations Declaration on the Rights of Indigenous People also affirm these rights. Moreover, documents such as the Convention on Biological Diversity and its supplementary document, the Nagoya Protocol, prescribe benefitsharing arrangements to be set in place where traditional knowledge or biological resources have been used for profit (Secretariat of the Convention on Biological Diversity, 2010). While not all are yet endorsed by the New Zealand government, these international instruments bring a focus to the conservation of biodiversity, an important principle at the heart of kaitiakitanga.

Acknowledging that in order to:

- Honour the Treaty of Waitangi and affirm the mana of hapū and iwi,
- Support the role of kaitiaki over taonga species,
- Uphold a high standard of ethics,
- Comply with relevant domestic and international policy,
- Create and benefit from commercial and non-commercial opportunities,
- Continue to advance scientific innovation, and
- Give effect to conservation of genetic resources for future generations.

A multi-layered and integrative approach is required.

These guidelines provide a comprehensive framework for research positioned at the intersection of genomics, innovation and Te Ao Māori. The guidelines also highlight the considerations at different levels of a project, from inception to completion. An engagement checklist provides questions to inform the development of robust relationships with Māori. It is intended that these guidelines be considered a living, evolving document with the understanding that as technology advances, so too will the specific needs to be addressed.



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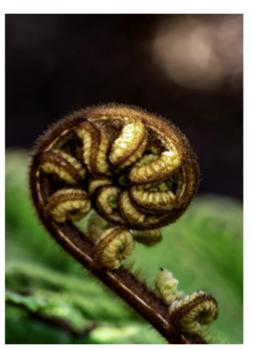
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**Engagement Framework** 

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Capacity Building
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# Te Nohonga Kaitiaki Guidelines Introduction

Research contributes to the broader developmental objectives of society. Ethics plays a specific role in guiding key behaviours, processes and methodologies used in research. Māori ethical frameworks recognise that all research in New Zealand is of interest to Māori and outline community expectations of appropriate behaviour in research to deliver the best outcomes for Māori (Atatoa-Carr et al., 2012; Beaton et al., 2017). This extends to research on taonga species. As such, all research that uses samples of taonga origin creates obligations on the part of institutions to act ethically and in good faith in relation to specific projects and future uses.

Genes are a basic unit of heredity and consist of a particular sequence of DNA located on a chromosome. Genetics is the study of genes and the molecular structure of genes, and is primarily concerned with their specific function and inheritance from one generation to another. A genome is the complete set of genetic information of an organism, including the spatial arrangement of that genetic information within a cell. The World Health Organization defines genomics as the study of genomes, which looks at the function of genes, as well as related techniques

(World Health Organization, 2004; World Health Organization, 2020). Genomics is broader in nature and encompasses all genes and their interrelationships in order to understand more fully their combined influence on the organism.

All research involving genetic resources for the purposes of conservation and ecology within Aotearoa is of value and interest to kaitiaki. Māori have expressed openness to working with genomic researchers where projects can help them meet their kaitiaki responsibilities alongside the use of mātauranga and more traditional interventions. Our engagements also identified a significant desire for mana whenua to understand the processes surrounding genomic research for the purposes of either mitigating inappropriate applications; or for the purposes of building knowledge or capacity while ensuring the integrity of taonga and mātauranga.

# **Purpose**

The Te Nohonga Kaitiaki Guidelines for Genomic Research on Taonga Species have primarily been developed as a tool to assist in the planning and execution of genomic research in a manner that honours taonga, kaitiaki and mātauranga Māori. This document has also been designed with mana whenua in mind, noting that these guidelines may serve as a starting point for hapū and iwi to formulate specific guidance that is relevant to their own tikanga and mātauranga. The development of this document serves to enhance engagement and dialogue, and in line with the rangatiratanga of iwi, hapū and whānau, is not intended to be authoritative in nature. As such, the guidelines are named Te Nohonga Kaitiaki, or the place of guardians, recognising both the role of traditional guardians of taonga species and the responsibilities of institutional stewards.

This document was designed to further build on the guidance provided in Te Mata Ira Guidelines on Genomic Research with Māori, Te Ara Tika Guidelines for Māori Research Ethics and He Tangata Kei Tua Guidelines for Biobanking. (Hudson et al., 2010; Hudson et al., 2016a; Hudson et al., 2016b; Hudson et al., 2016c). Te Nohonga Kaitiaki guidelines were developed with a focus for the future and are oriented towards empowering iwi, hapū and whānau to navigate genomic innovation in Aotearoa. The guidelines aim to assist in formulating an approach to research that is consistent with the Crown's everemerging response to Wai 262, as well as address the growing need to come into compliance with

international practices consistent with the Nagoya Protocol.

The guidelines have been designed with a number of objectives. They are:

- To honour Te Tiriti o Waitangi/The Treaty of Waitangi,
- To affirm the rangatiratanga of kaitiaki over taonga species,
- To reiterate the mana of hapū and iwi,
- To support Māori data sovereignty over data generated from research,
- To address the need for benefit sharing arrangements in compliance with the emerging global standard under the Nagoya Protocol.
- To establish practical guidance for institutions to conduct research in a manner that reflects cultural responsiveness and ethical science.

'Taonga species' refers broadly to any species or biota that are of value to Māori. The holistic nature of the Māori paradigm means that taonga species are viewed in the entirety of their living contexts. This means that taonga species can be viewed as both independent entities and as interdependent parts of complex ecosystems. This means that taonga can be viewed on macro and micro levels and thus can include bioactives, microbes, including bacteria, as well as species of flora, fauna and entire ecosystems. This is explained in more detail in the Cultural Foundation section of these guidelines.

Kaupapa Māori research has been defined as research by Māori, for Māori and with Māori (Smith, 2012). Although not all genomic research will necessarily fit within all of the parameters described here, the objectives and characteristics of furthering rangatiratanga and giving full recognition to Māori values and systems that are central to kaupapa Māori research remain key when dealing with taonga (Collier-Robinson et al., 2019; Pihama et al., 2002; Walker et al., 2006).

Genomics Aotearoa funded the development of the Te Nohonga Kaitiaki guidelines. The first round of consultation involved a review of literature as well as series of nationwide hui<sup>1</sup>, presentations and wananga<sup>2</sup> held between 2018 and 2019. These hui were attended by both science and community stakeholders, including representation from various government departments and Crown entities. Interviews with key informants were also carried out in a manner that captured the diverse nature of taonga species research and its potential applications. Eleven formal submissions were received in the first consultation round from a range of institutions and individuals<sup>3</sup>, and five further submissions were received in the second consultation round4.

<sup>&</sup>lt;sup>1</sup> These initial hui were held in Auckland, Ngaruawaahia, Hamilton, Christchurch and Dunedin between June and November 2018, with a total of 193 participants.

<sup>&</sup>lt;sup>2</sup> This overnight wānanga was held from 30th September to 1st October 2019 at the Waikato-Tainui Research College in Hopuhopu, Ngaruawaahia.

<sup>&</sup>lt;sup>3</sup> Submissions from institutions were received from the Genomics Aotearoa Kāhui Māori, Species Aotearoa, NIWA, The University of Auckland, Te Papa Atawhai, New Zealand's Biological Heritage Challenge, Manaaki Whenua Landcare Research and four individuals.

<sup>&</sup>lt;sup>4</sup> Submissions were received from Species Aotearoa, Manaaki Whenua Landcare Research and three individuals.

# **Guiding Principles**

The guiding principles have been set in place to guide the thinking around genomic research. They speak primarily to the importance of how communities relate to the nature of the project.

In the absence of guidelines, falling back on guiding principles should inform good decisionmaking. The guiding principles in this document reflect those set out in the Te Mata Ira Guidelines.

### Kia tau te wairua o te tangata

Wairua represents the spirit in which a taonga is shared and used. It encompasses the intentions, expectations and duties of care that are embedded in the use of the taonga. It requires a level of trust between traditional kaitiaki and the institutional stewards to whom the taonga is being entrusted for the purposes of the research.

'Kia tau te wairua o te tangata' sets the standard of comfort that communities should have with a given research project. The level of comfort may change over time and therefore it is important for researchers to maintain ongoing communication with mana whenua in order to keep mana whenua informed and engaged at every phase of the research.

### Kia pūmau te mana o te tangata

Mana translates to power and authority and refers to the authoritative ability of kaitiaki to exercise their tino rangatiratanga.

'Kia pūmau te mana o te tangata' speaks to maintaining a level of control that enables kaitiaki to exercise their self-determination over their taonga. More specifically, it relates to the level of control that participants and communities have with regard to the research project.

# Kia hiki te mauri o te kaupapa

As described earlier, mauri is a core concept that underpins the Māori paradigm. It is the essence of life and encapsulates ecosystemic balance and the biological integrity of life-sustaining systems and conditions.

'Kia hiki te mauri o te kaupapa' makes clear the importance of ensuring that the integrity of systems that contribute to research endeavours is enriched, or at the very least maintained throughout the course of the research.

# **Operating Principles**

The operating principles are reflective of the nature and relationship of whānau, hapū and iwi with taonga. The operating principles provide clarity around how relationships with the taonga

are to be navigated when planning research and are of particular utility in the absence of applicable guidance.

### He whakapapa tō te taonga

### Taonga have relationships with people and place.

'He whakapapa tō te taonga' acknowledges the vast and extensive reaches of whakapapa that contribute to the unique history of a taonga and its state of being. In this sense, whakapapa is not exclusively tied to ancestry, but encompasses each connection that enriches it with relational identity. From this perspective, we view any taonga not only as a treasure or resource, but in the light of all relationships that have culminated in its existence. 'He whakapapa tō te taonga' describes the genealogical, social, ecological, spiritual and historical relationships that cumulatively shape the highly nuanced identity of a taonga.

### He mauri tō te taonga

### Taonga are essential components of the ecosystem.

'He mauri tō te taonga' encompasses the delicate interplay between all organisms, which in turn form the foundations of ecosystem balance. Mauri as it relates to genomic research speaks to the importance of the preservation of distinct populations, the preservation of biodiversity, the preservation of roles within ecosystems and the preservation of mātauranga. 'He mauri tō te taonga' is the acknowledgement that taonga are central to ecosystemic health.

# He kaitiaki tō te taonga

### Taonga are protected through intentional action.

As described throughout this document, one of the key underpinning aspects of Te Ao Māori is the taonga-kaitiaki relationship. 'He kaitiaki tō te taonga' speaks to the significance of this relationship and reinforces that taonga should be actively protected. It is an acknowledgement that whether through the self-determined actions of kaitiaki or the responsibility of institutional stewards, taonga are to be given due care and regard.

# **Engaging with Māori**

An important part of conducting genomic research that involves taonga species is the need to engage with the right people. Māori have repeatedly expressed their desire to be involved in research conversations from the earliest stage possible. While whānau, hapū and iwi are able to identify appropriate connections between taonga and kaitiaki, the nature of this involvement may vary from case to case.

It should be noted that genomic research has a fraught and often controversial history for Māori and Indigenous communities. Many will assert their right to say NO, in line with the Aashukan Declaration (NZAIA, n.d.). Others will only participate if their cultural intellectual property rights, as reflected in the Mataatua Declaration, are upheld (The Mataatua Declaration on the Cultural and Intellectual Property Rights of Indigenous Peoples, 1993).

The responsibility to engage with an appropriate voice lies with the entity seeking engagement and this should begin at the earliest possible time. Before beginning consultation, it is important to apply careful thought regarding who is being consulted and whether they have the mana or authority to represent the interests of their community. It may also be wise to consider concurrent consultation. In some instances, individual iwi or hapū may opt to be represented by a rūnanga or iwi collective that may be better resourced or oriented, in order to represent their needs.

The following table summarises who researchers could engage with in the development of research projects. Though not an exhaustive list, it identifies where discussions may need to happen and where agreements might need to be made.

Through engagement with the appropriate people it is possible to develop research projects that enhance relationships based on good faith and mutual understanding (Te Arotūruki, 2009). Engaging with Māori in the design process enables:

- an acknowledgement of rangatiratanga status as Treaty partners
- an acknowledgement that mātauranga Māori can make an important contribution
- an acknowledgement that Māori have resources and capability to contribute; and
- an acknowledgement that for some issues Māori are better placed to develop the solutions (Te Arawhiti, 2018a; Te Arawhiti, 2018b).

Others examples of guidelines to support effective engagement include Bay of Plenty Regional Council (2011), Auckland Council (2016) and Waikato Regional Council (2017).

# Who to engage with

Mana Whenua	
Individual whānau or hapū	Engage with whānau and/or hapū that have exclusive and well-defined kaitiakitanga interests for a specific variant of a taonga species.
Rūnanga or an iwi entity	Engage with iwi to gain support for projects and to identify their kaitiakitanga interests in specific taonga species.
Mātauranga holders – Kaitiaki and Tohunga	Kaitiaki (guardians) have a responsibility to care for the taonga and will often be experts (tohunga) or hold expert knowledge (mātauranga) that can add value to projects.
Multiple iwi and/or multiple collective iwi entities	Multiple iwi may share kaitiakitanga responsibilities for certain taonga species, and instances such as this should involve engagement with all interested parties.
Māori	
Māori researchers	Māori researchers with expertise in the project or whakapapa to iwi within the rohe.
Māori networks and liaisons	Māori networks with an interest in the project or Māori liaisons affiliated with relevant organisations.
Māori commercial and non-commercial entities	Māori commercial entities may have an interest in ascertaining the novelty or bioactivity of a certain taonga species in order to develop commercial enterprises based on the authenticity or provenance of the taonga, or to prevent non-Māori and off-shore entities from doing the same.





# **Engagement** Framework

### Levels of Responsibility

The question of 'what constitutes good engagement' is challenging from the outset. While Māori have expressed views of being 'over consulted', what has also been expressed is a keen desire to be involved and engaged with early in a manner that is both comprehensive and meaningful. One of the limitations of Crownimposed requirements for consultation embedded in policy is that engagement with Māori has become more about procedural compliance than an opportunity to build mana-enhancing relationships as a foundation for a project.

The Te Nohonga Kaitiaki Engagement Framework has been developed to illustrate the considerations that lay the foundation for effective engagement. Satisfactory engagement is not one-dimensional and comprises different levels of responsiveness, with each level encompassing its own considerations. The various levels illustrated have been highlighted to bring attention to the nuances involved in planning research involving Māori and their taonga.

The Te Nohonga Kaitiaki Engagement framework outlines effective engagement with Māori across three levels of responsiveness; at the Project Level, the Organisation Level and Systems Level. Each level of responsiveness is detailed in following pages.

Project Level Responsiveness Project Outcomes
Level of Involvement
Intellectual Contribution
of Māori/Mana Whenua
Engagement/
Communication

Organisation Level Responsiveness Capacity Building Embedding Relationships Sample/Data Access and Governance Benefit Sharing

System Level Responsiveness

End Users Research Networks and Consortia International Agreements Research Funding

# Project Level Responsiveness

Project Level Responsiveness encompasses issues that are directly relevant to the project itself.

The four main aspects as indicated previously include:

- Whether good engagement and communication practices have been set in place
- Whether project outcomes are mutually beneficial and understood
- An understanding of involvement for all parties involved
- How the intellectual contribution of Māori and mana whenua will be recognised.

Useful questions can include the following:

### **Engagement/Communication:**

- When should engagement occur?
- How is engagement conducted?
- Is there an adequate level of cultural understanding prior to engagement?
- Is there an adequate level of understanding of the Treaty prior to engagement?
- What are the parameters of consent or denial?
- Will kaitiaki have the resources made available to them to be fully informed about the project and what it aims to achieve?
- Who absorbs the cost of engagement?

### **Project Outcomes**

- What are the intended project outcomes?
- Who benefits from these outcomes?

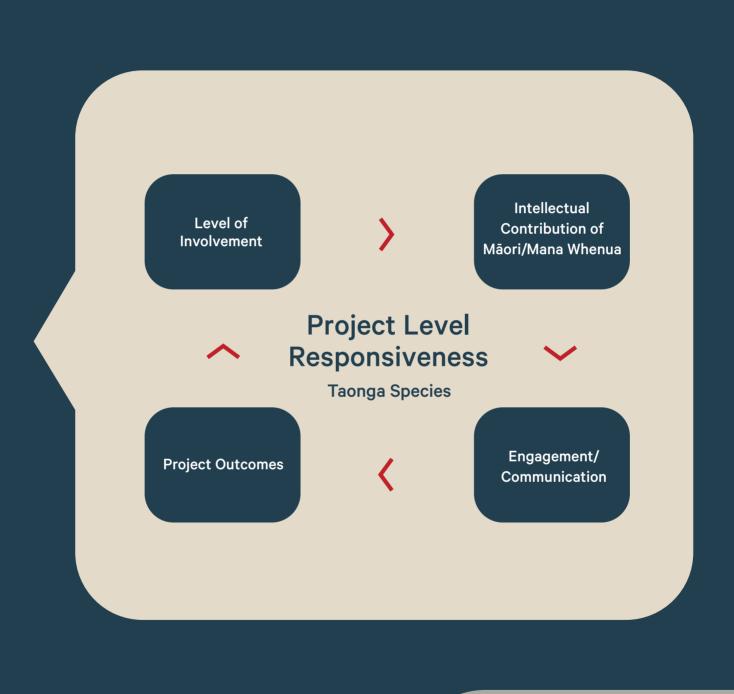
- What are the potential benefits to Māori?
- What are the potential risks?
- Have there been conversations with Māori to establish what their long term vision and priorities may be?
- Is there an alignment of desired outcomes from this project?
- What efforts have been made to ensure all parties have a mutual understanding of those outcomes?
- Is there a future vision for collaboration?

### Level of Involvement

- What are the roles and responsibilities for kaitiaki within this collaboration?
- What expectations do Māori have of researchers?
- What expectations do researchers have of Māori?
- Are roles, responsibilities and expectations practicable?
- What is the level of project resourcing?

# Intellectual Contribution of Māori/Mana Whenua

- What is the level of understanding in relation to mātauranga Māori?
- Is there an understanding of Māori approaches to protecting their mātauranga and taonga?
- How has mātauranga Māori strengthened research?
- How can the project support/substantiate/ confirm mātauranga Māori?



# Organisation Level Responsiveness

Organisation Level Responsiveness speaks to the organisation's roles and responsibilities in navigating the 'how' of the project.

This level of responsiveness covers the following four aspects:

- Data access and governance of data has been considered
- · A plan for fair and equitable benefit sharing
- Consideration of capacity-building aspirations and mechanisms
- Relationships established in good faith.

Useful questions can include the following:

### Sample/Data Access and Governance

- Are there any legal or moral requirements for data from research to be made public or shared with a third party?
- Where are data derived from and is there any secondary usage of data?
- What are the data access protocols?
- Who gets to design data access protocols?
- How does that process take place?
- Are Māori involved in decisions about access and use of new data?
- How will samples be obtained?
- What are the protocols around sample management?
- Are Māori involved in the decisions about sample management?

### **Benefit Sharing**

- What benefit-sharing processes are in place?
- Has thought been given to new knowledge that may emerge from the project?
- What entity gets to benefit from new knowledge?
- What, if any, IP rights are there over the knowledge generated and how was this negotiated?
- Are there agreements or mechanisms in place that allow for sharing of benefit in relation to any potential new knowledge that may emerge from research?
- How are original agreements maintained if 'parties' change or are terminated?

### **Capacity Building**

- What initiatives support scientists to better understand Te Ao Māori?
- What initiatives support Māori to better understand Science?
- Are there any absorptive capacities (human, technical, relational – kaupapa, mātauranga, tikanga) built into the project?

### **Embedding Relationships**

- How are Māori involved in making decisions in the project?
- Is Māori input valued?
- Is open communication supported on both ends?



# System Level Responsiveness

System Level Responsiveness pertains to aspects external to the project that are beyond the scope of the organisation. These aspects can include the national and international legal parameters of the research, or the extent to which the research can be disseminated. System Level Responsiveness is important to be aware of at the project and organisation levels in order to mitigate any potential limitations that the project may have as a result.

The four aspects to be taken into account include:

- Research Networks and Consortia
- National Policies and International Agreements
- Research Funding and Publications
- End Uses and End Users.

Useful questions can include the following:

### Research Networks and Consortia

 What interests will other networks and consortia have in data generated from the project?

### International Agreements

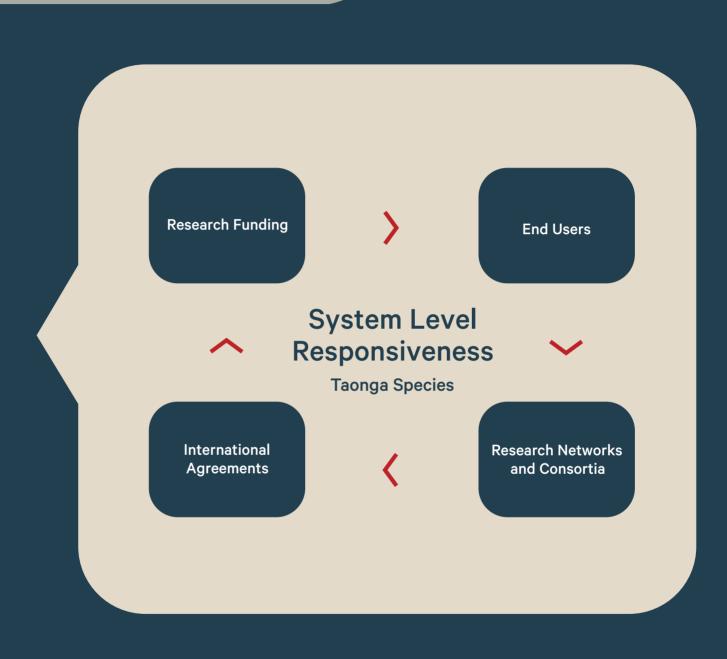
- What effect does domestic policy have on the project?
- What international agreements have an impact on the project?
- How do international agreements affect the project?

### **Research Funding**

- What funding opportunities may arise from this project for follow-on projects?
- Do the opportunities for funding come with conditions that may conflict with kaitiaki values?

### **End Users**

- What is the end use of the project?
- Is there foreseeable potential for other uses from the outputs of this project?
- Do the foreseeable potential uses align with the values and aspirations of kaitiaki?
- Are there foreseeable uses that may harm kaitiaki, their values or their aspirations?
- Has there been consideration of the potential unforeseen future uses that may arise from the project?
- Who are the primary end users of the project?
- Who are the potential secondary users of the project?



# References

- Atatoa-Carr, P., Hudson, M., Kingi, T. K, & Moore, A. (2012). Āhuatanga ū ki te tika me te pono mō te Rangahau Māori: Māori Research Ethics: An overview. National Ethics Advisory Committee. <a href="https://neac.health.govt.nz/assets/Uploads/NEAC/publications/neac-maori-research-ethics-an-overview-2012.pdf">https://neac.health.govt.nz/assets/Uploads/NEAC/publications/neac-maori-research-ethics-an-overview-2012.pdf</a>
- Auckland Council. (2016). Lessons for successful Mana Whenua engagement: Tips for people who don't know where to start. Auckland New Zealand: Auckland Council. <a href="https://knowledgeauckland.org.nz/media/1265/lessons-for-successful-mana-whenua-engagement\_final-print.pdf">https://knowledgeauckland.org.nz/media/1265/lessons-for-successful-mana-whenua-engagement\_final-print.pdf</a>
- Bay of Plenty Regional Council. (2011). Engaging with Māori: A guide for staff of the Bay of Plenty Regional Council. Whakatāne, New Zealand: Māori Policy Unit, Bay of Plenty Regional Council. <a href="https://www.boprc.govt.nz/media/717746/engagement-toolkit.pdf">https://www.boprc.govt.nz/media/717746/engagement-toolkit.pdf</a>
- Beaton, A., Hudson, M., Milne, M., Port, R. V., Russell, K., Smith, B., Toki, V., Uerata, L., Wilcox, P., Bartholomew, K., & Wihongi, H. (2017). Engaging Māori in biobanking and genomic research: a model for biobanks to guide culturally informed governance, operational, and community engagement activities. Genetics in Medicine, 19(3), 345-351. <a href="https://www.nature.com/articles/gim2016111">https://www.nature.com/articles/gim2016111</a>
- Collier-Robinson, L., Rayne, A., Rupene, M., Thoms, C., & Steeves, T. (2019). Embedding Indigenous principles in genomic research of culturally significant species: a conservation genomics case study. New Zealand Journal of Ecology, 43(3), 3889 <a href="https://www.frontiersin.org/articles/10.3389/fpubh.2020.00111/full">https://www.frontiersin.org/articles/10.3389/fpubh.2020.00111/full</a>
- Environmental Protection Authority (2016). Incorporating Māori perspectives into decision-making. Environmental Protection Authority. <a href="https://www.epa.govt.nz/applications-and-permits/engaging-with-maori/incorporating-maori-perspectives/">https://www.epa.govt.nz/applications-and-permits/engaging-with-maori/incorporating-maori-perspectives/</a>
- Hudson, M., Milne, M., Reynolds, P., Russel, K., & Smith, B. (2010). Te Ara Tika Guidelines for Māori research ethics; A framework for researchers and ethics committee members. Health Research Council of New Zealand. <a href="https://www.hrc.govt.nz/resources/te-ara-tika-guidelines-maori-research-ethics-0">https://www.hrc.govt.nz/resources/te-ara-tika-guidelines-maori-research-ethics-0</a>
- Hudson, M., Beaton, A., Milne, M., Port, W., Russel, K., & Smith, B., Toki, V., Uerata, L., & Wilcox, P.(2016a) Te Mata Ira: Guidelines for Genomic Research with Māori. Te Mata Hautū Taketake- Māori and Indigenous Governance Centre, The University of Waikato. <a href="https://www.waikato.ac.nz/\_data/assets/pdf\_file/0018/321534/Te-Mata-Ira-Genome-Research-Guidelines.pdf">https://www.waikato.ac.nz/\_data/assets/pdf\_file/0018/321534/Te-Mata-Ira-Genome-Research-Guidelines.pdf</a>
- Hudson, M., Beaton, A., Milne, M., Port, W., Russel, K., & Smith, B., Toki, V., Uerata, L., Wilcox, P.(2016b). He Tangata Kei Tua: Guidelines for Biobanking with Māori. e Mata Hautū Taketake- Māori and Indigenous

- Governance Centre, The University of Waikato <a href="https://www.waikato.ac.nz/\_data/assets/pdf\_file/0019/321535/He-Tangata-Kei-Tua-Biobanking-Guidelines.pdf">https://www.waikato.ac.nz/\_data/assets/pdf\_file/0019/321535/He-Tangata-Kei-Tua-Biobanking-Guidelines.pdf</a>
- Pihama, L., Cram F., Walker, S. (2002). Creating methodological space: A literature review of Kaupapa Maori research. Canadian Journal of Native Education, 26(1), 30-43. <a href="https://www.researchgate.net/profile/Fiona-Cram/publication/234647374\_Creating\_Methodological\_Space\_A\_Literature\_Review\_of\_Kaupapa\_Maori\_Research/links/5c354a6692851c22a366072d/Creating-Methodological-Space-A-Literature-Review-of-Kaupapa-Maori-Research.pdf">Kaupapa-Maori-Research.pdf</a>
- Secretariat of the Convention on Biological Diversity. (2010). Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from their Utilization to the Convention on Biological Diversity. <a href="https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\_no=XXVII-8-b&chapter=27&clang=\_en">https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\_no=XXVII-8-b&chapter=27&clang=\_en</a>
- Smith, L. T. (2012). Decolonizing methodologies: Research and indigenous peoples (Second edition). Zed Books. <a href="https://www.waikato.ac.nz/fmis/research-practice/publications/decolonizing-methodologies">https://www.waikato.ac.nz/fmis/research-practice/publications/decolonizing-methodologies</a>
- Te Arawhiti. (2018a). Crown Engagement with Māori. Crown Engagement with Māori
- Te Arawhiti. (2018b). Guidelines for Engagement with Māori. <a href="https://www.tearawhiti.govt.nz/tools-and-resources/crown-engagement-with-maori/">https://www.tearawhiti.govt.nz/tools-and-resources/crown-engagement-with-maori/</a>
- Te Arotūruki. (2009).Te Arotūruki process: a process for effective cross-cultural dialogue on science. <a href="http://www.dabhand.co.nz/tap/index.html">http://www.dabhand.co.nz/tap/index.html</a>
- The Mataatua Declaration on the Cultural and Intellectual Property Rights of Indigenous Peoples. (1993). <a href="https://ngaaho.maori.nz/cms/resources/mataatua.pdf">https://ngaaho.maori.nz/cms/resources/mataatua.pdf</a>
- Waikato Regional Council. (2017). Māori engagement framework: He ritenga mahitahi. Hamilton, New Zealand: Waikato Regional. Council. <a href="https://www.waikatoregion.govt.nz/assets/WRC/Council/Policy-and-Plans/11340016-Maori-Engagement-Framework-Guide.pdf">https://www.waikatoregion.govt.nz/assets/WRC/Council/Policy-and-Plans/11340016-Maori-Engagement-Framework-Guide.pdf</a>
- Waitangi Tribunal. (2011). Ko Aotearoa Tēnei: A Report into Claims Concerning New Zealand Law and Policy Affecting Māori Culture and Identity (Wai 262, 2011). <a href="https://forms.justice.govt.nz/search/WT/reports/reportSummary.html?reportId=wt\_DOC\_68356606">https://forms.justice.govt.nz/search/WT/reports/reportSummary.html?reportId=wt\_DOC\_68356606</a>
- Walker, S., Eketone, A., & Gibbs, A. (2006). An exploration of kaupapa Maori research, its principles, processes and applications. International Journal of Social Research Methodology, 9(4), 331–344. <a href="https://www.tandfonline.com/doi/full/10.1080/13645570600916049?casa\_token=U-dxO7yKZpoAAAAA%3AKCZ2X1GoEgWgHsqzZ4IA0ATWzh6pN6SDamUkTeSRu9NtY8U6w2c7kb\_F\_afzxi3sZo4t9YEo58nVKQ">https://www.tandfonline.com/doi/full/10.1080/13645570600916049?casa\_token=U-dxO7yKZpoAAAAA%3AKCZ2X1GoEgWgHsqzZ4IA0ATWzh6pN6SDamUkTeSRu9NtY8U6w2c7kb\_F\_afzxi3sZo4t9YEo58nVKQ</a>
- World Health Organization. (2004). Genomics and World Health, Fifty Seventh World Health Assembly Resolutions and Decisions. WHA57/2004/REC/1. Geneva, 17-22 May. <a href="https://apps.who.int/gb/ebwha/pdf\_files/WHA57\_A57\_REC1-en.pdf">https://apps.who.int/gb/ebwha/pdf\_files/WHA57\_A57\_REC1-en.pdf</a>
- World Health Organization. (2020). Human genomics in global health: WHO definitions of genetics and genomics. https://www.who.int/genomics/geneticsVSgenomics/en/



# Appendix A: Te Nohonga Kaitiaki Engagement Checklist

# Appendix A: Te Nohonga Kaitiaki Engagement Checklist

This checklist includes considerations relating to the appropriate parties to engage with when planning research, and also the issues to be considered as they relate to the levels of responsiveness, as outlined earlier in this document. These considerations work together to form a preferable standard of engagement in undertaking research around taonga species.

	Engaging with Māori	Yes / No?
Engaging the correct people	Are there multiple parties that may have overlapping kaitiaki interests?	
	Do the representatives that have been engaged have the mandate or support of their whānau, hapū or iwi?	
Who has been engaged with?		

	Project Level Responsiveness	Completed?
Engagement & Communication	Adequate engagement resourcing – Engaging party should absorb cost of engagement.	
	Engagement is conducted early on in project timeframe.	
	Engagement is conducted face to face (kanohi ki te kanohi).	
Level of Involvement	Scope of project and understanding of level of collaboration: Understand what roles and responsibilities will be within collaboration. Level of project resourcing.	
Intellectual Contribution of Mana Whenua / Māori	Understanding of: Mātauranga Māori Māori approaches to IP rights and Taonga Mātauranga Māori is used to strengthen research Mātauranga Māori will play a critical part in the future of New Zealand.	
Project Outcomes	Mutual understanding of the project and project outcomes.	
	Demonstrating of benefits to both parties.	
	Future vision of collaboration.	
	Ensure project builds capacity into mana whenua.	

	Organisational Responsiveness	Completed?
Sample/Data Access and Governance	Has there been thought given to where data is derived from?	
	Is there a protocol around publications?	
	Have protocols around data access and sample management been considered?	
Benefit Sharing	Rights to intellectual property are well defined.  Opportunities for benefit sharing have been throughly discussed and implemented.	
Capacity Building	Consideration given to absorptive capacities (human, technical, relational – kaupapa, mātauranga, tikanga).	
Embedding Relationships	Have structural relationships been established?  There is a commitment to these relationships being maintained in good faith.	

	System Level Responsiveness	Have these issues been addressed?
End Users	This includes participants and stakeholder engagment that may have unique or competing views on the topic.	
	Have potential end users and stakeholder participants been identified?	
	The amount and type of stakeholder engagement will vary depending on the project and topic.	
Research Funding	The funding opportunities will vary depending on the project and topic.	
International Agreements	Has consideration been given to the international agreements that may impact on Māori?	
	Recognition is to be given to Māori as per normal expected processes.	
Research Networks & Consortia	It will vary depending on the project and topic.	



# Appendix B: List of Guidelines for Genetic Research with Māori

# Appendix B: List of Guidelines for Genetic Research with Māori

On the following pages is a list of key guidelines that address use of genomic material in 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.	https://gateway.hrc.govt.nz/f unding/Guidelines_for_rese archers_on_healh_research_ involving_Mori.pdf
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 international perspective.'	http://www.hrc.govt.nz/news -and-publications/publicatio ns/te-ara-tika-guidelines-m %C4%81ori-research-ethics- framework-researcher
Te Arotūruki	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.	http://www.dabhand.co.nz/ta p/index.html

Te Mata Ira	Developed primarily for application in medical genomics area. Cultural framework and logic based on experiences of Māori communities.	http://www.waikato.ac.nz/_d ata/assets/pdf_file/0018/321 534/Te-Mata-Ira-Genome-R esearch-Guidelines.pdf
He Tāngata Kei Tua	Framework developed for biobanking/ tissue banking.	https://www.waikato.ac.nz/ data/assets/pdf_file/0019/3 21535/He-Tangata-Kei-Tua- Biobanking-Guidelines.pdf
EPA	Resources developed to support HSNO-required consultation processes.	https://www.epa.govt.nz/app lications-and-permits/enga ging-with-Māori/
Mātaatua Declaration	Mātaatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples.	https://www.wipo.int/export/ sites/www/tk/en/databases/ creative_heritage/docs/mat aatua.pdf
Vision Mātauranga	A Guide to Vision Mātauranga: Lessons from Māori Voices in the New Zealand Science Sector.	https://www.buildingbetter.n z/publications/Rauika_Mang ai_A_guide-to-Vision_Matau ranga.pdf
Consultation with Māori	Research consultation with Māori (Otago University policies).	http://www.otago.ac.nz/rese arch/Māoriconsultation/
Aashukan Declaration	Declaration on engagement for Impact Assessments with Indigenous Peoples.	https://www.nzaia.org.nz/indi genouspeoples.html
CARE Principles	CARE Principles for Indigenous Data Governance.	https://www.gida-global.org/ care
Māori Data Sovereignty Principles	Te Mana Raraunga Principles for Māori Data Sovereignty.	https://www.temanararaung a.maori.nz/nga-rauemi



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