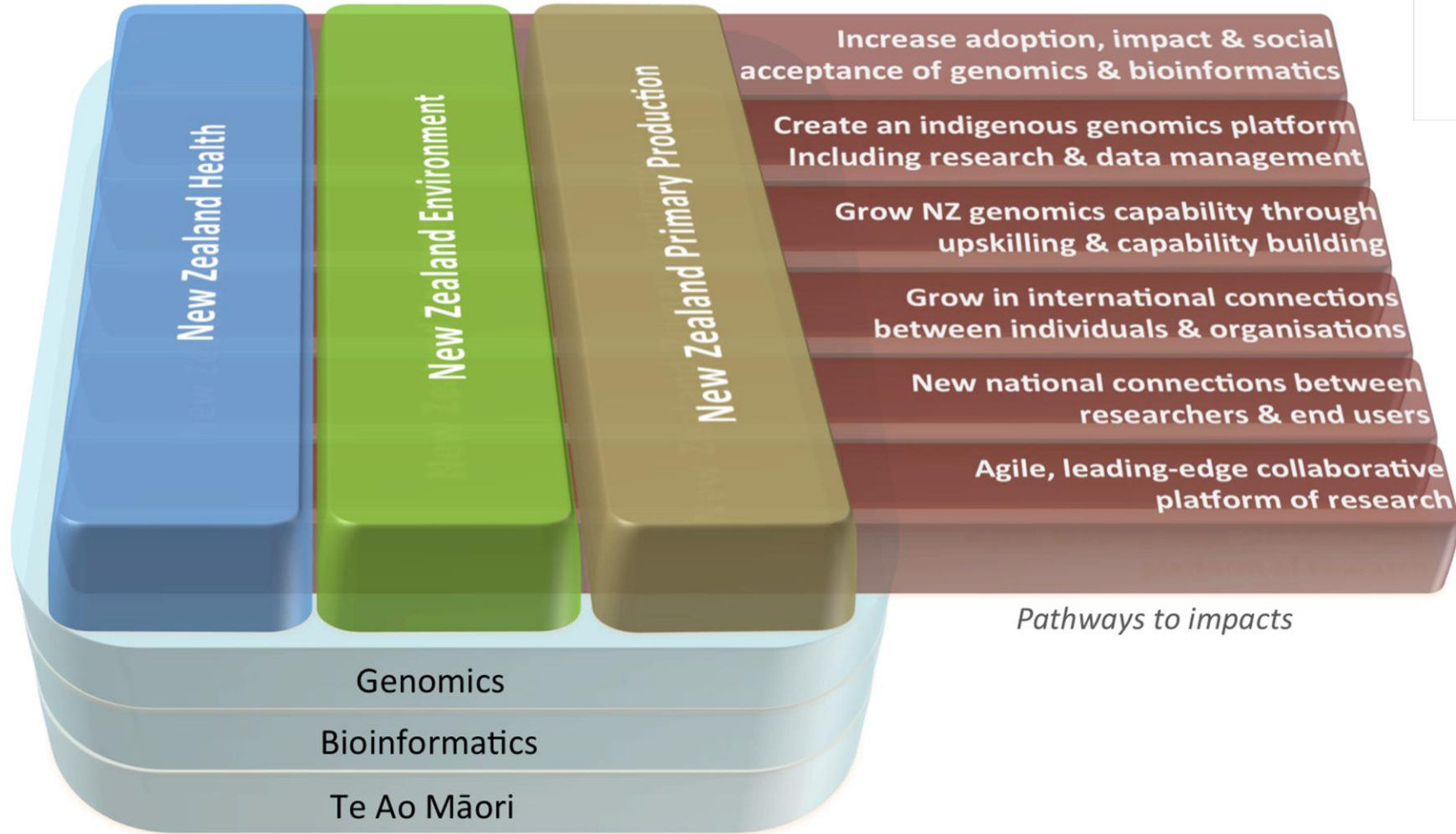


Enhancing Māori Control of Genomic Data



Genomics Aotearoa

Research projects within 3 themes



Underpinning infrastructure



Māori Guidelines for Genomic Research

- Te Mata Ira Guidelines for Genomic Research with Māori
- He Tangata Kei Tua Guidelines for Biobanking with Māori
 - Tissue is a taonga
 - Data is a taonga
 - Taonga needs to be managed
- *Te Nohonga Kaitiaki Guidelines for Genomic Research with Taonga Species*
 - *All native species are taonga, introduced species can be taonga, biota and bioactives associated with taonga species are taonga*
 - *Whakapapa, mauri, mana, tapu, and kaitiaki are integral to taonga*
- Cultural, Ethical & Commercial aspects to Consider



Reconceptualising Taonga

Taonga Relationship	Nature of Relationship	Interests	Rights
Primary Taonga Relationship	Any prized or valued thing or concept that exists within Te Ao Māori	“A taonga is something treasured or valued within the framework of the human element or lens. From an Ao Māori perspective this includes all species. Values are dynamic across time and space/place.”	Tangata whenua have a rights to all indigenous flora and fauna of Aotearoa
Secondary Taonga Relationship	Any aspect, feature, part of a primary taonga that cannot exist in isolation of the whole.	“Taonga, represents a connection, a process of value, have value to iwi or potential value to Maori.”	Where a right exists to a taonga species, this also includes a right to the microbial components, bioactives and all unique properties that comprise its makeup.
Tertiary Taonga Relationship	Anything that plays an instrumental role in the support, revitalisation, maintenance, and overall well being of a taonga.	“All things are important and nothing exists in isolation.”	Tangata whenua have rights in relation to organisms that contribute to maintaining the essence of a taonga species

Thompson, A. (2018). Reconceptualising Taonga. Te Nohonga Kaitiaki Discussion Document. Genomics Aotearoa.

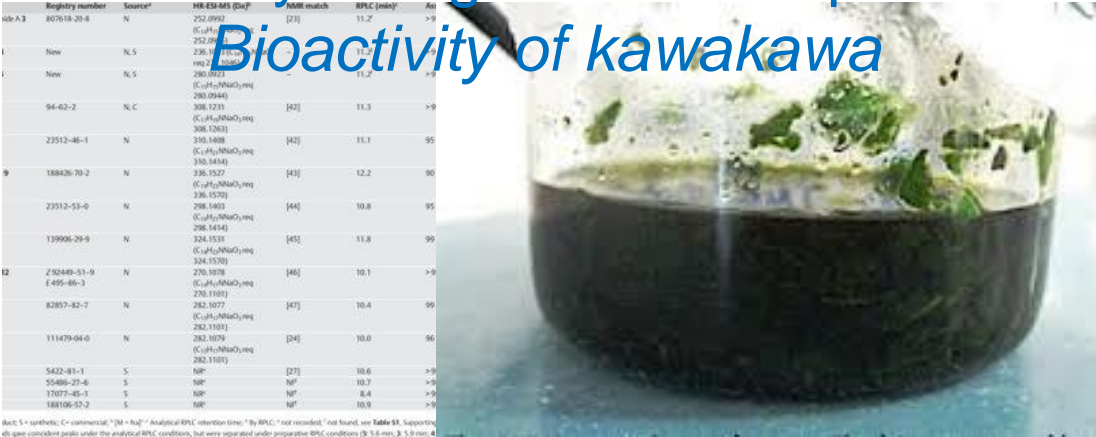


Primary taonga relationship:
Kawakawa

Tertiary taonga relationship:
Microorganisms in the ngahere supporting kawakawa



Secondary taonga relationship:
Bioactivity of kawakawa



THE CHALLENGE OF COMPETING INTERESTS

1. 'Indigenous' support for open data and open science
2. Increasing 'Indigenous' participation in cutting edge science and technology
3. 'Indigenous' aspirations for Indigenous Data Sovereignty

Goal: for Indigenous communities to benefit from innovation and development via greater control of Indigenous knowledge and Indigenous data

INDIGENOUS DATA SOVEREIGNTY

TOWARD AN AGENDA

Edited by TAHU KUKUTAI
and JOHN TAYLOR



'A debate-shaping book ... it speaks to a fast-emerging field; it has a lot of important things to say; and the timing is right.'

— Stephen Cornell, Professor of Sociology
and Faculty Chair of the Native Nations Institute,
University of Arizona



PRESS

ISBN 9781760460303 (Print) ISBN 9781760460310 (Online) CAEPR RESEARCH MONOGRAPH NO. 38

This book is available to download for free or hard copies are available to purchase from:
press.anu.edu.au/publications/series/centre-aboriginal-economic-policy-research-caepr/indigenous-data-sovereignty

Intellectual Property Rights & Cultural Intellectual Property

- **Intellectual Property Rights**

- Copyright
- Patent
- Plant Variety Right
- Allows you to use them
- Allows you to stop others using them
- Enforcability
 - Courts & Police

- **Cultural Intellectual Property**

- Indigenous knowledge or mātauranga Māori
- Cultural heritage information
- Genomic sequences of taonga species
- Assert responsibility for them
- Protocols to manage use of them
- Enforcability through ethical expectations/moral obligations

*Note: Naturally occurring Genes, proteins, and chemicals can't be patented, GMO's can be.
NCAI Intellectual Property Rights in Biomedical Research, 20/03/19*





Māori Data Sovereignty and Intellectual Property

Indigenous
Labels

Maori Data
Repository

Maori Data
Governance

Trade Secret

Intellectual
Property
Rights

Public
Data

Restricted Data

Protected
Data

Maori Data Sovereignty

Māori control of Māori data



Māori Data Sovereignty and Intellectual Property

**Indigenous
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Restricted Data: Maori Data
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Data

Maori Data Sovereignty

Māori control of Māori data

Genomics Aotearoa: Māori Data Repository

- Many countries are now regulating data sharing
- GA is proposing a *managed access* approach for researchers and publishers, through an application process.
- Not a 'public' resource
- Researchers make applications to access data from the repository
- Access and storage to be managed within a Māori values framework



Māori Values Framework

- The Māori values framework is a 'living' approach:
- Facilitated by the Kāhui Māori of Genomics Aotearoa as the decision maker
- Consistent with Māori guidelines
 - Te Mata Ira Guidelines for Genomic Research with Maori
 - He Tangata Kei Tua Guidelines for Biobanking with Maori
- Consents and permissions of tangata whenua, authorities, and genomic sample originators (obtained by the researchers)



Access Principles

- Māori community;
 - *Research consultation and engagement is crucial to inform the data repository of community intentions.*
- Māori relationship with taonga does not alter despite changing form from: original → sample → data → report → IP.
 - *Knowledge is not held as a universal right. It is lived, experienced and held by tohunga and kaitiaki with responsibilities.*
 - *Knowledge is held within cultural context. Not reduced to lifeless data sitting in isolation from that cultural context.*




Indigenous Origin Labels

Inbox - maui@waikato.ac.nz - Th... Traditional Knowledge (TK) Label: x


Not secure | localcontexts.org/tk-labels/

Apps Gmail PET MBIE | MBIE Portal Air New Zealand: B... Facebook - Log In o... Twitter Te Mana Raraunga... SING Aotearoa Google Scholar Uni Fleet Bookings

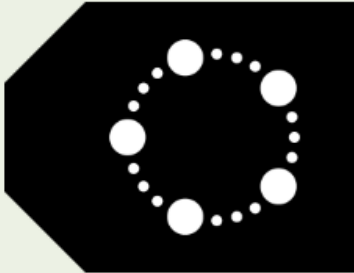
LOCAL contexts About TK Labels CI Labels TK Label Hub Educational Resources Sharing




TK Multiple Communities (TK MC)




TK Non-Verified (TK NV)




TK Family (TK F)



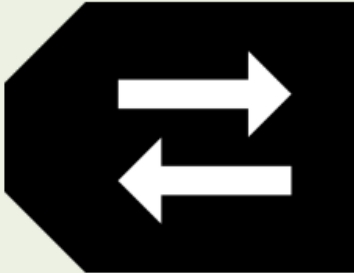
TK Seasonal (TK S)




TK Outreach (TK O)



TK Verified (TK V)



TK Attribution (TK A)



TK Community Use Only (TK CO)

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Indigenous provenance fields

Inbox - maui@waikato.ac.nz - Th... x Biocode Field Information Manag... x

https://geome-db.org


Apps Gmail PET MBIE | MBIE Portal Air New Zealand: B... Facebook - Log In o... Twitter Te Mana Raraunga... SING Aotearoa Google Scholar Uni Fleet Bookings

GeOMe

QUERY ABOUT WORKBENCH


Genomic Observatories MetaDatabase (GeOMe)

The Genomic Observatories Meta-Database (GeOMe) is a web-based database which captures metadata on biological samples. GeOMe satisfies the requirements of the [genomic observatories model](#), including capturing the who, what, where, and when associated with all samples.




About

Learn more about GeOMe



Query

Search and download sequence files and associated metadata



Workbench

View and manage project specific data

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MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND



IRA MOANA

GENES OF THE SEA · AOTEAROA · NEW ZEALAND
COLLABORATIVE NETWORK + DATABASE

Libby Liggins

Senior lecturer, Massey University

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A COMMITMENT TO INDIGENOUS GENOMICS SPANS THE GLOBE

International Group responding to calls for 'Unrestricted Access to Genomic Data', and providing an **Indigenous perspective on access to Indigenous Genomic Data**.

Garrison, NA., Hudson, M., Ballantyne, LA., Garba, I., Martinez, A., Taulii, M., Arbour, L., Caron, NR., & Rainie, SC. **Genomic Research Through an Indigenous Lens: Understanding the Expectations**. Annu. Rev. Genom. Hum. Genet. 20:6.1–6.23. 2019.

Claw, K.G, Anderson, M.Z., Begay, R.L., Tsosie, K.S., Fox, K., & Garrison, N.A. **A framework for enhancing ethical genomic research with Indigenous communities**. Nature Communications. 9:2957, 2018.

Hudson, M., Wilcox, P., Smith, B., Beaton, A., Milne, M., & Russell, K. CELSI-us: **Reducing Friction with Indigenous Communities in Genomic Research**. American Anthropologist. 120(2), 330-332, 2018.

SING USA; SING Aotearoa; SING Canada

SING Aotearoa 2019





genomics
aotearoa

Nga mihi ki a koutou

