

WHAT DOES 'ETHICAL RESEARCH' LOOK LIKE? AN INDIGENOUS PERSPECTIVE ON BIG DATA & PRECISION MEDICINE

Maui Hudson
24 March 2022



LAND ACKNOWLEDGEMENT

“I acknowledge and celebrate the ancestors on whose traditional lands we meet, and pay my respects to their elders past and present”

“I acknowledge and celebrate Waikato-Tainui on whose traditional lands I live, and pay my respects to their elders past and present”

Ko Makeo te maunga / Makeo is my mountain

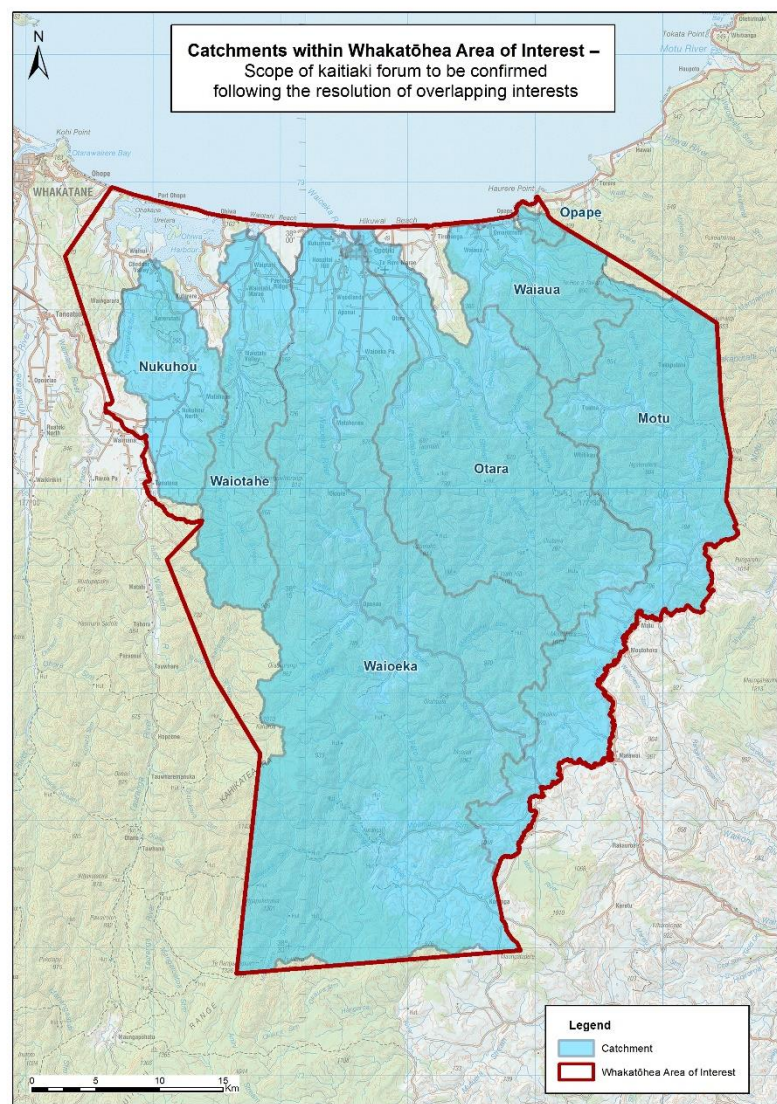
Ko Waiaua te awa / Waiaua is my river

Ko Mataatua te waka / Mataatua is my ocean crossing canoe

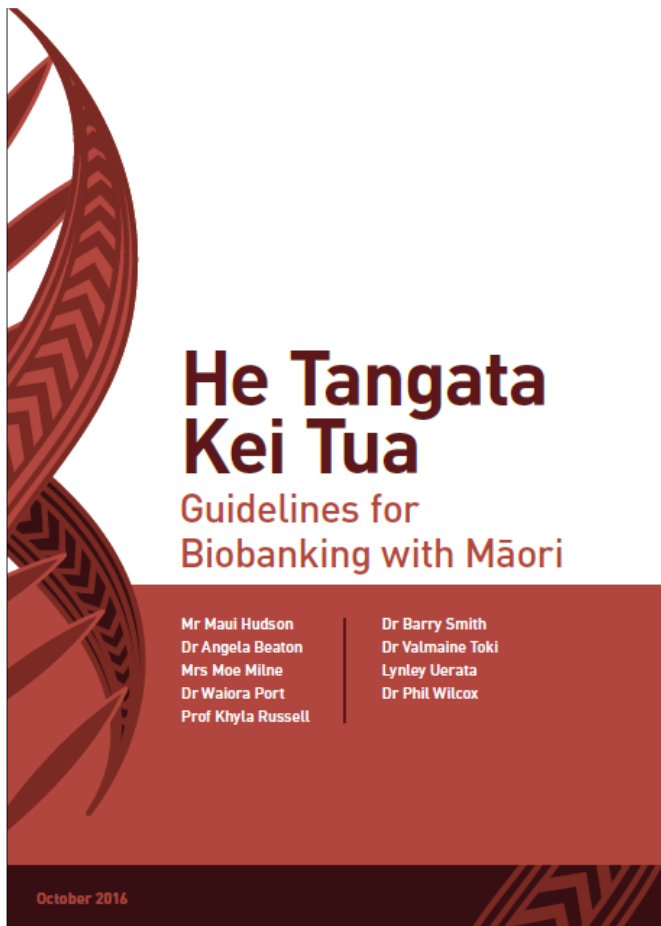
Ko Whakatōhea te Iwi / Whakatōhea is my tribe

Ko Maui Hudson toku ingoa / Maui Hudson is my name

MY COUNTRY: TE ROHE O TE WHAKATŌHEA



INDIGENOUS GUIDELINES FOR GENOMICS

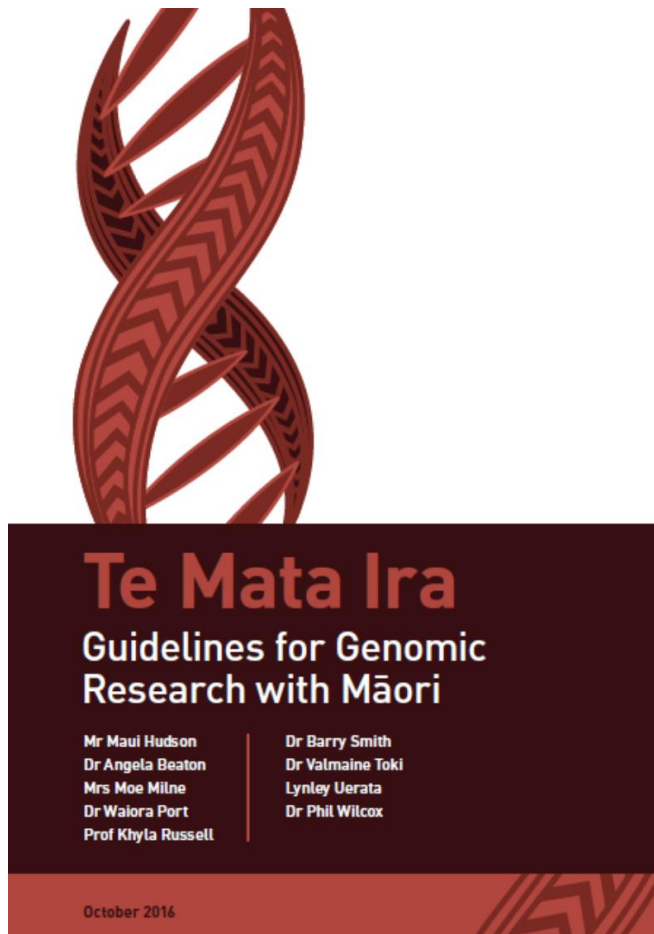


He Tangata Kei Tua
Guidelines for
Biobanking with Māori

Mr Maui Hudson
Dr Angela Beaton
Mrs Moe Milne
Dr Waiora Port
Prof Khyla Russell

Dr Barry Smith
Dr Valmaine Toki
Lynley Uerata
Dr Phil Wilcox

October 2016

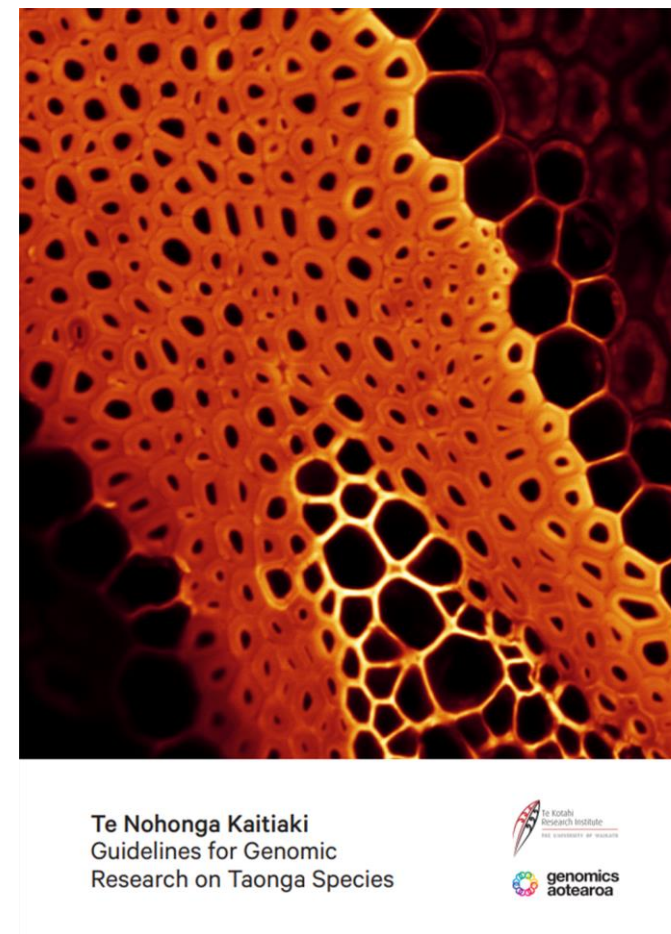


Te Mata Ira
Guidelines for Genomic
Research with Māori


Mr Maui Hudson
Dr Angela Beaton
Mrs Moe Milne
Dr Waiora Port
Prof Khyla Russell

Dr Barry Smith
Dr Valmaine Toki
Lynley Uerata
Dr Phil Wilcox

October 2016



Te Nohonga Kaitiaki
Guidelines for Genomic
Research on Taonga Species

 Te Kotahi
Research Institute
the government of new zealand


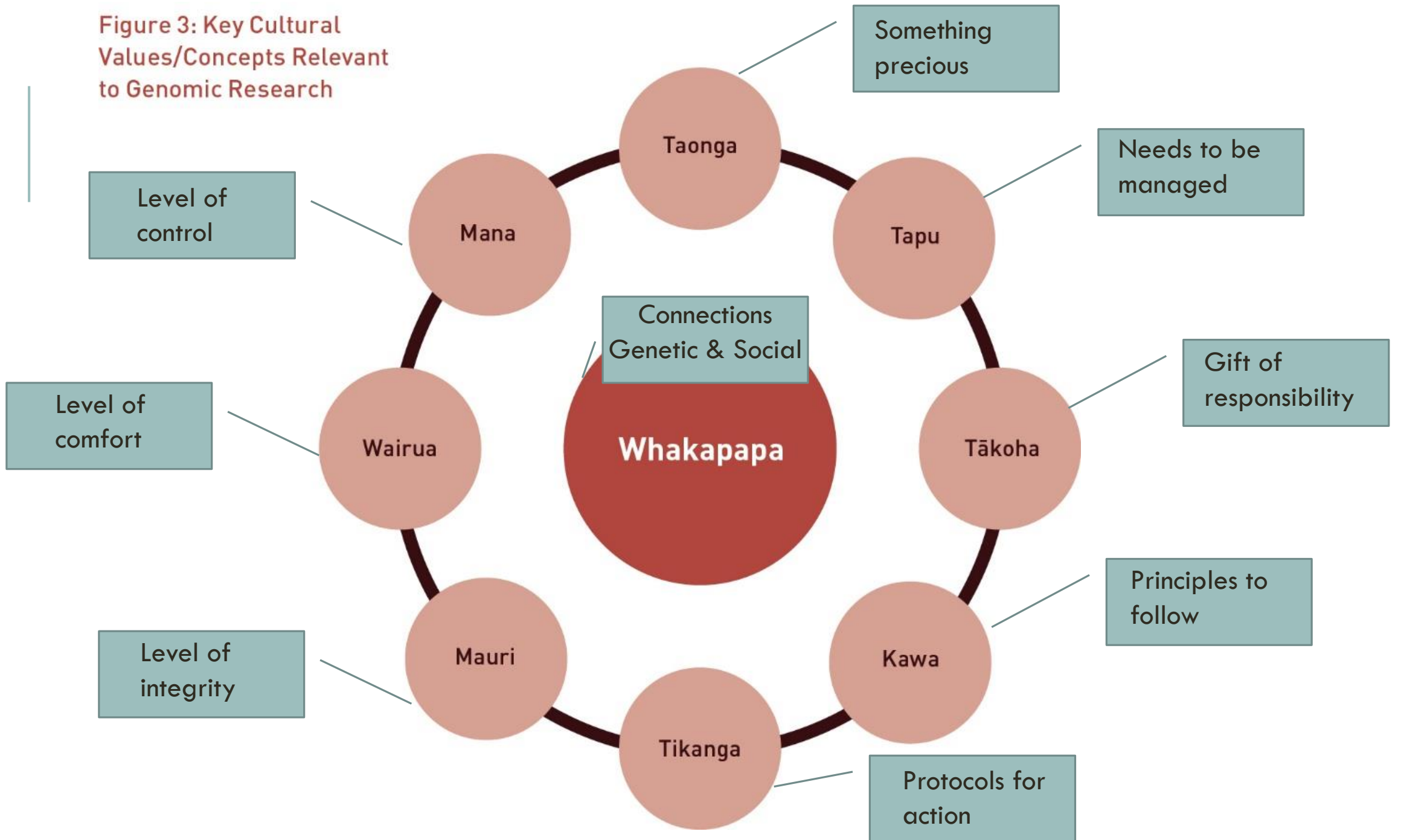
 genomics
aotearoa

Figure 3: Key Cultural Values/Concepts Relevant to Genomic Research



KAWA & TIKANGA

Principles

Kia tau te wairua o te tangata
(level of comfort)

Kia pūmau te mana o te tangata
(level of control)

Kia hiki te mauri o te kaupapa
(level of integrity)

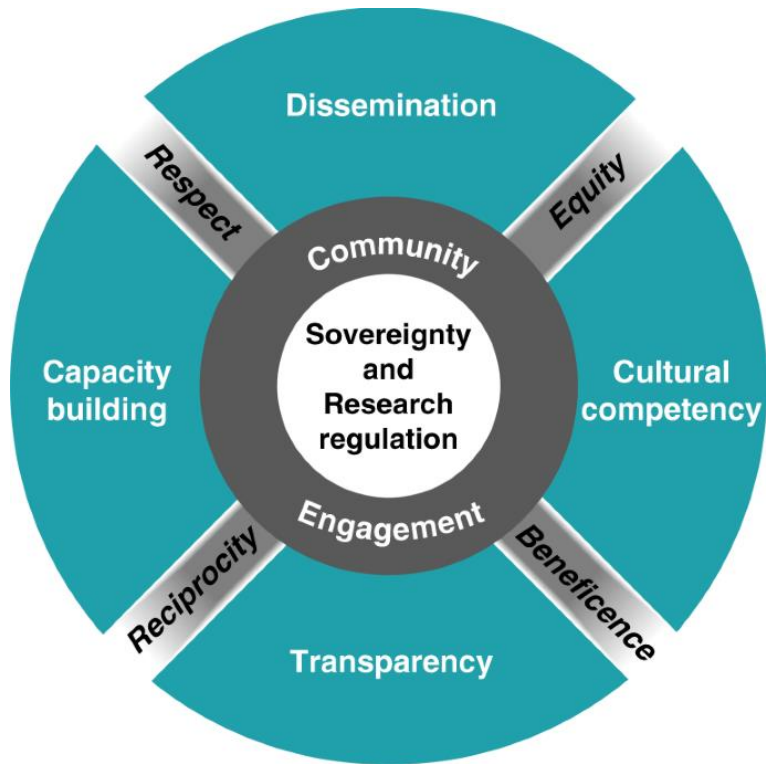
Protocols

Te Tuku i te Taonga
(sharing the gift)

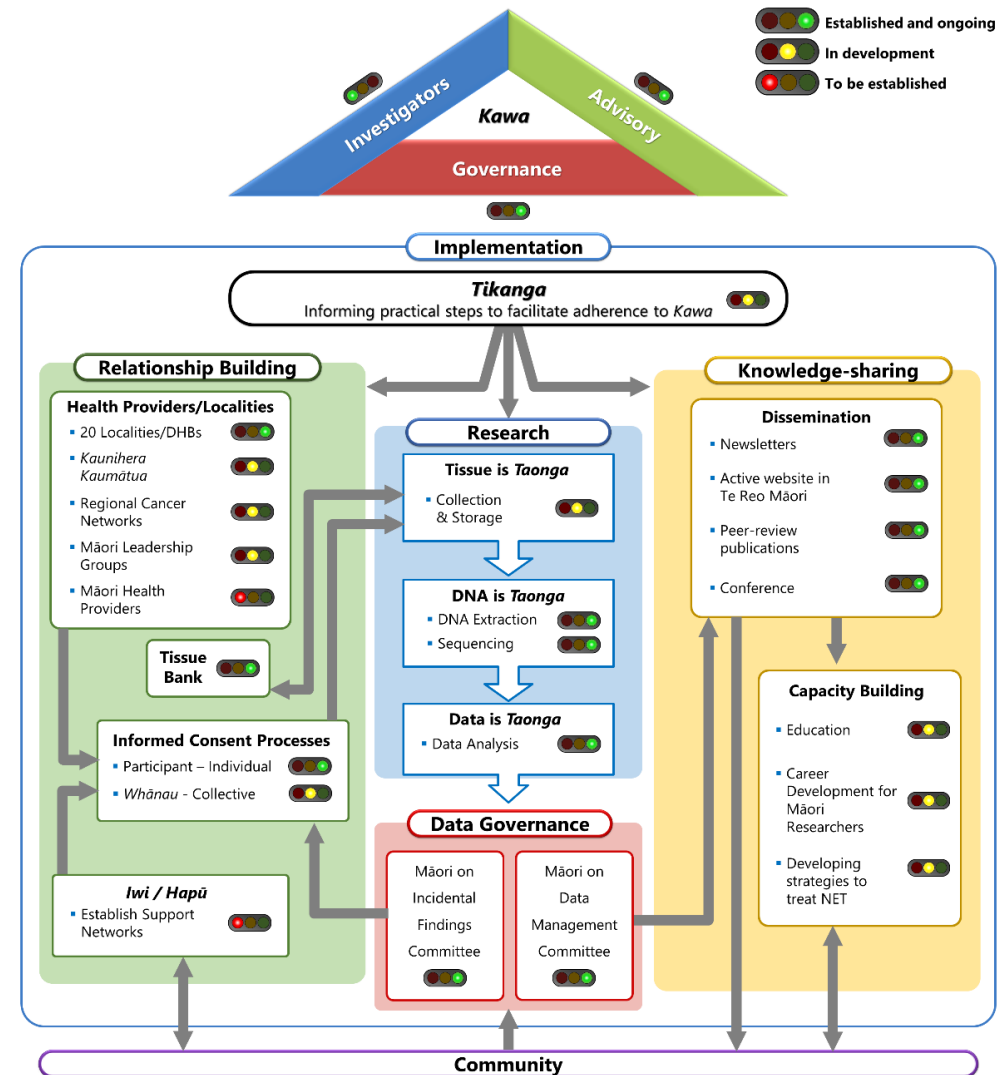
Te Hau o te Taonga
(the spirit of the gift)

Te Whakahoki i te Taonga
(returning the gift)

INFORMING BETTER RESEARCH PRACTICES



Claw, K.G., Anderson, M.Z., Begay, R.L. et al. A framework for enhancing ethical genomic research with Indigenous communities. *Nat Commun* 9, 2957 (2018). <https://doi.org/10.1038/s41467-018-05188-3>



Henare KL, Parker KE, Wihongi H, Blenkiron C, Jansen R, Reid P, Findlay MP, Lawrence B, Hudson M, Print CG. Mapping a route to Indigenous engagement in cancer genomic research. *Lancet Oncol.* 2019 Jun;20(6):e327-e335. doi: 10.1016/S1470-2045(19)30307-9. PMID: 31162106.

About



Under Indigenous Governance, NCIG conducts research and other activities to build and maintain a **genome resource for the research community.**





Summer Internship for INdigenous peoples in Genomics



SING



WHAT WAS THE MOST POWERFUL PART OF YOUR SING EXPERIENCE?

“Before coming to SING, I was very reluctant to discuss my experiences or perspectives as a Native American because I felt uncomfortable othering myself in an environment (university) where I already felt like an outsider. Fortunately, meeting other Native students helped me learn, gave me the confidence to speak up, and provided me with a network of friends to share experiences and grow throughout our careers and our lives.”

- Previous SING USA Participant



[SING Canada](#)



[SING Aotearoa](#)



[SING Australia](#)



[SING USA](#)



SING INDIGENOUS GENOMICS CONFERENCE 2020

23/24 JANUARY 2020 | UNIVERSITY OF WAIKATO | HAMILTON, NZ



SING Indigenous Genomics Conference

134 Registered Participants



SING Alumni Gathering

42 Attendees



CREATING A NEW FOUNDATION FOR BIOLOGY

Sequencing Life for the Future of Life





PROVENANCE OF INDIGENOUS DATA

INDIGENOUS DATA SOVEREIGNTY

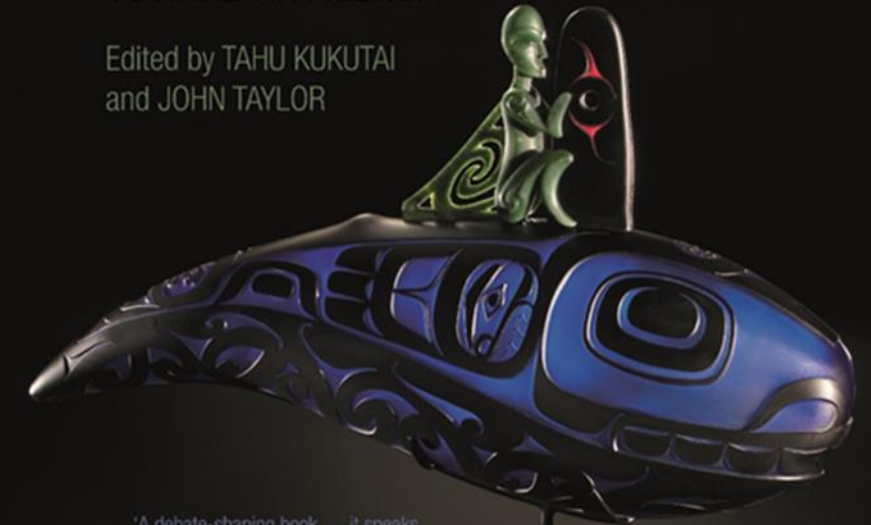
Indigenous Data Sovereignty is a discourse about rights and interests

- Indigenous / Treaty rights
 - Cultural Intellectual Property rights
 - Indigenous research ethics, data ethics
1. **Data for Governance:** Gaining access to use data to transform the lives of our people.
 2. **Governance of Data:** Managing access to data to ensure use is relevant and responsive.

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

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

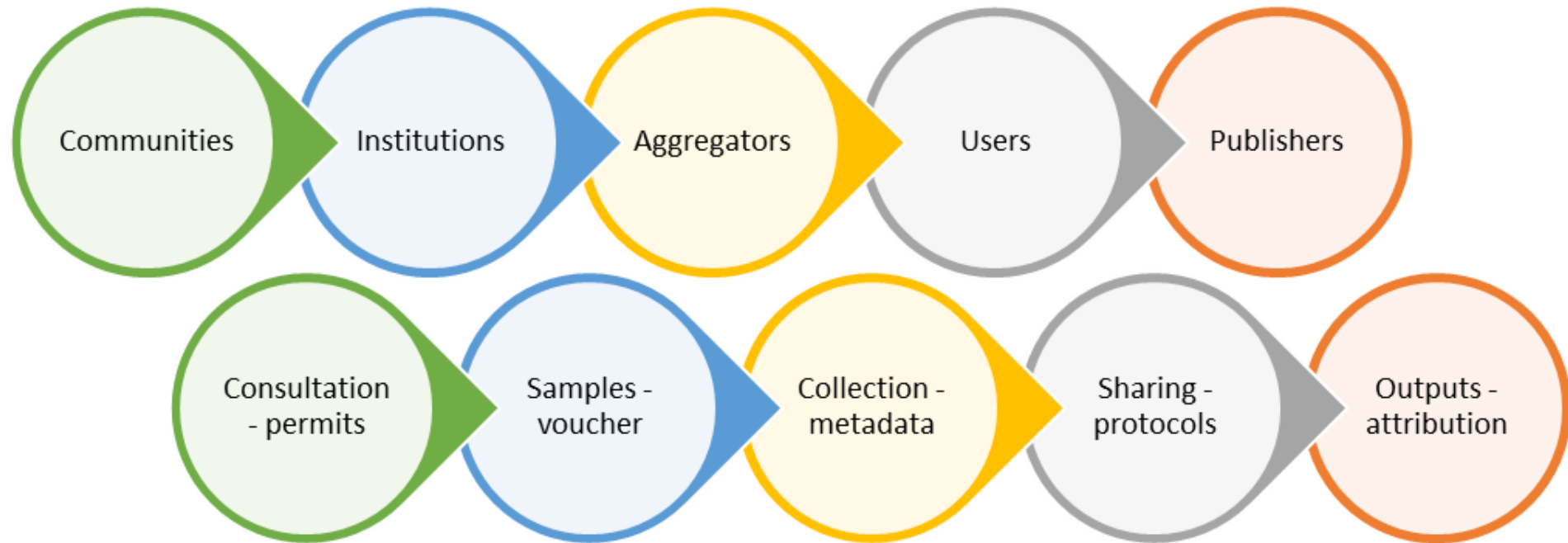
Goal: for Indigenous communities to benefit from innovation and development via greater control of Indigenous knowledge and Indigenous data

Routledge Studies in Indigenous Peoples and Policy

INDIGENOUS DATA SOVEREIGNTY AND POLICY

Edited by
Maggie Walter, Tahu Kukatui,
Stephanie Russo Carroll
and Desi Rodriguez-Lonebear

MAINTAINING PROVENANCE ACROSS DATA ECOSYSTEMS



PRINCIPLES FOR USE OF INDIGENOUS GENOMIC DATA

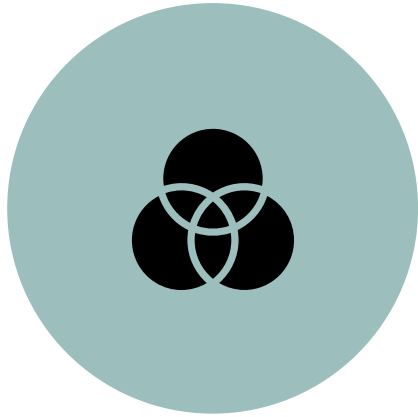
HUDSON ET AL (2020). RIGHTS, INTERESTS & EXPECTATIONS: INDIGENOUS VIEWS ON UNRESTRICTED ACCESS TO GENOMIC DATA. NATURE REVIEW GENETICS

Building Trust: Indigenous communities decide whether their genomics data and associated metadata are publically available or accessible on request;

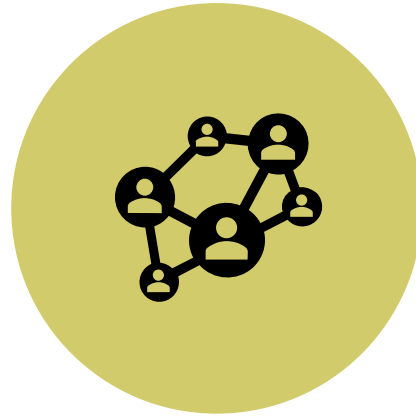
Enhancing Accountability: the provenance of Indigenous samples and genomics data must be transparent, disclosed in publications, and maintained with the data; and

Improving equity: credit should be given to Indigenous communities to support future use and benefit sharing agreements as appropriate.

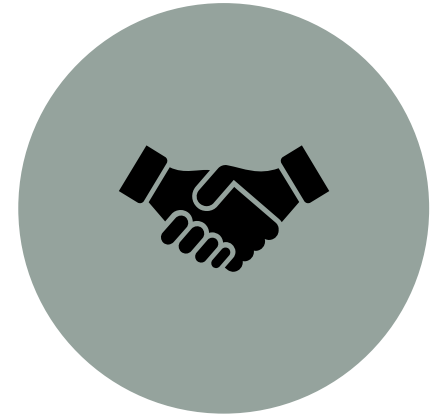
ACCOUNTABILITY IN DATA USE: ISSUES FOR INDIGENOUS PEOPLES



HOW TO **RECOGNIZE** INDIGENOUS RIGHTS AND INTERESTS IN RAW DATA AND DSI WITHIN AN OPEN DATA ENVIRONMENT



HOW TO **SHARE** DSI, AND COLLABORATE AROUND ETHICAL ACCESS AND USE, IN WAYS CONSISTENT WITH EXISTING COMMUNITY PROTOCOLS



HOW TO **NEGOTIATE** EQUITABLE OUTCOMES FROM THE USE OF DSI INCLUDING POTENTIAL COMMERCIALIZATION

TK Labels



TK Attribution
(TK A)



TK Clan
(TK CL)



TK Family
(TK F)



TK Multiple
Communities
(TK MC)



TK Outreach
(TK O)



TK Non-Verified
(TK NV)



TK Verified
(TK V)



TK Non-
Commercial
(TK NC)



TK Commercial
(TK C)



TK Culturally
Sensitive
(TK CS)



TK Community
Voice
(TK CV)



TK Community
Use Only
(TK CO)

BC Labels



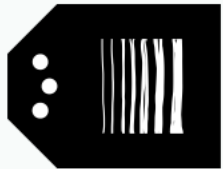
BC Research Use
(BC R)



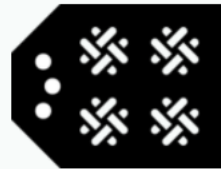
BC Open to
Collaboration



BC Open to
Commercialization



BC Provenance
(BC P)



BC Multiple
Communities
(BC MC)



BC Clan
(BC CL)



BC Consent
Verified
(BC CV)



BC Consent Non-
Verified
(BC CNV)



BC Outreach
(BC O)



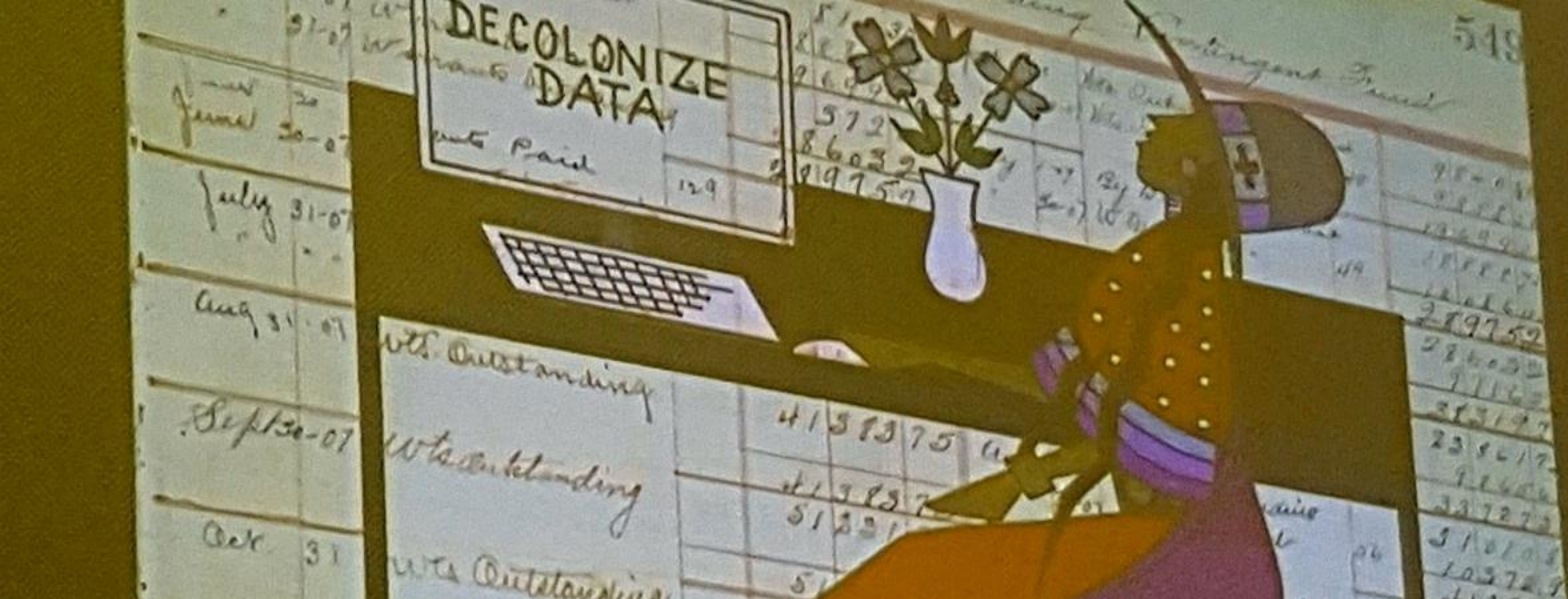
BC Non-
Commercial
(BC NC)

WHAT THE TK & BC LABELS COMMUNICATE

<p>Provenance</p>	
<p>Protocols</p>	
<p>Permissions</p>	

WHAT'S HAPPENING IN AOTEAROA NZ





INDIGENOUS CONTROL OF INDIGENOUS DATA
INDIGENOUS CONTROL OF INDIGENOUS NARRATIVES
INDIGENOUS CONTROL OF INDIGENOUS ASPIRATIONS



SENAHD
Southeast Native American
Health Data