

Mihimihi and Karakia (Opening welcome, spoken in te reo Māori)



Rare Disorders Research Forum 2026

hosted by **Rare Disorders New Zealand**, the **New Zealand Rare Disorders Research Network**, and the **New Zealand ERDERA National Mirror Group**, with financial support from the **Catalyst Fund**, **University of Otago**, and **Oxford Nanopore**

Pepeha (≈ who am I?)

- Ko Moumoukai, Whakapunake nga maunga
- Ko Te Wairoa hōpupu hōngenge matangirau, Kopuawhara, nga Nuhaka nga awa
- Ko Kahungunu, Tākitimu, Te Rākātō nga marae
- Ko Tākitimu, Kurahaupo nga waka
- Ko Ngāti Kahungunu, Rongomaiwahine, Ngāti Rakaipaaka, nga iwi
- Ko Ngāi Te Rakatō, Ngāi Te Apatu, Te Whare Rau o Te Tahinga nga hapu
- The mountains are Moumoukai and Whakapunake
- The rivers are the Wairoa, Kopuawhara and the Nuhaka
- The ancestral houses are Kahungunu, Tākitimu, Te Rākātō
- The ancestral canoes are Tākitimu and Kurahaupo
- The iwi are Ngāti Kahungunu, Rongomaiwahine, Ngāti Rakaipaaka
- The sub tribes are Ngāi Te Rakatō, Ngāi Te Apatu, Te Whare Rau o Te Tahinga



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- | | |
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E

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G

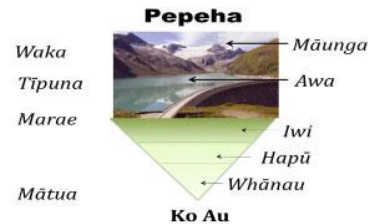
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Quantitative Genetics

$$P = G + E$$

Phenotype = Genotype + Environment

-> Pepeha is the conceptual equivalent of this...



Tikanga and Mātauranga Māori ENABLES
genomic resource development for Māori (and
non-Māori)

- We've led the world in developing tools for precision health that have combined cutting edge science and traditional knowledge to deliver health outcomes not previously possible...
- He Kākano has already been used for >400 families diagnoses not previously possible
- He Kākano also used for improved diagnosis in non-Māori(!!)



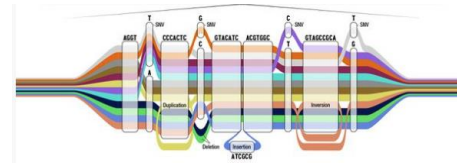
He Kākano has already changed the diagnostic landscape

- variants that look rare (and therefore suspicious) in European-dominant databases turn out to be *common and benign* in He Kākano

- when a variant is genuinely rare within the correct ancestral context, we are more confident it is disease-causing

→ Leads to improved equity of access to genomic diagnosis

Clinicians and overseas laboratories asking about He Kākano



Addressing Global Underrepresentation in Genomics: Pangenomics Grounded in an Indigenous Māori Ethical Framework

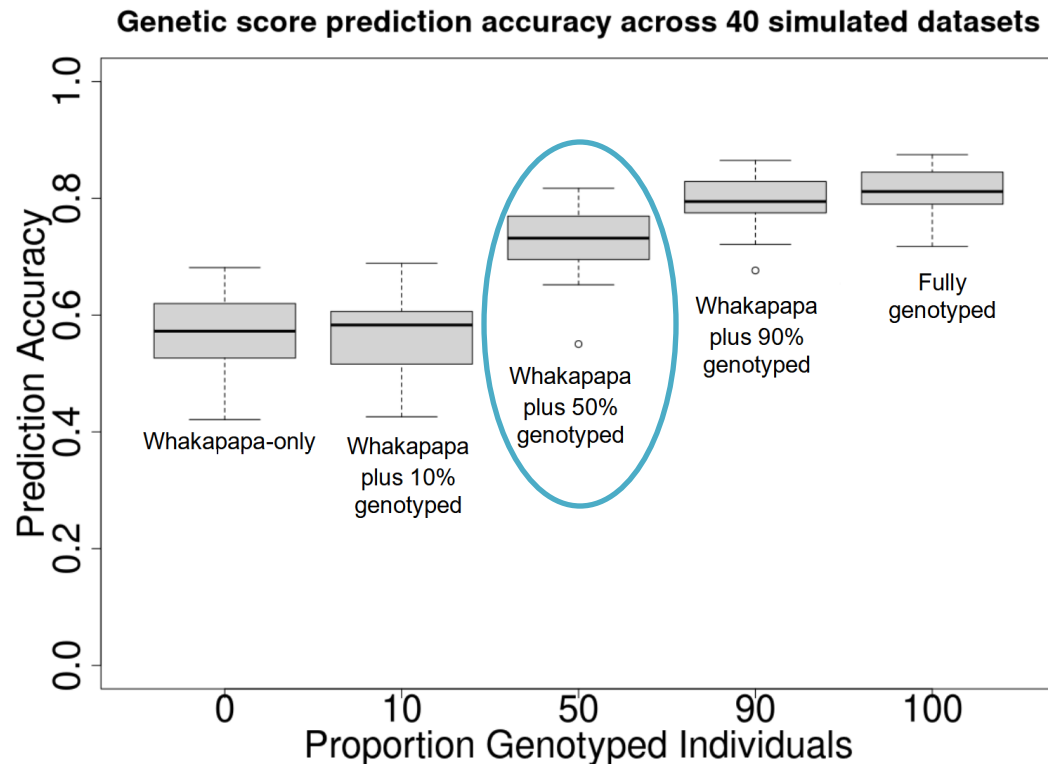
Ann M. Mc Cartney^{40,2}, Benjamin J. Halliday^{40,4}, David M. Markie⁴, Julian K. Lucas², Brandy M. McNulty², Elizabeth Goodin^{4,5}, Ivo Violich², Joshua Gardner², Tyler McInnes², Dinindu Senanayake⁴, Jian Sheng Boey⁴, Matt Bixler⁶, Brandon Pickett¹, Linelle Ann L. Abueg², Todd Hillaker², Celine Naudet⁶, Helen Whitham^{10,10,3}, Anna Rolleston^{11,12,10}, Maui Hudson^{14,14,10}, Irene Kereama-Royal^{15,16,10}, Andrew Spurr^{17,20,10}, Jason Alexander^{19,20,10}, Nadine Hapuku^{21,22,10}, Ben Te Aika^{23,24,10}, Jennie Harré-Hindmirk²⁰, Tuta Haerora^{25,26,10}, Huti Puketapu-Watson^{27,28,10}, Stephen P. Robertson⁴, Karen H. Miger⁴⁰, Phillip L. Wilco^{24,27,30}

*Authors contributed equally to this work

** Corresponding authors



Disease Risk Estimation (= prognoses for precision health) using whakapapa is MUCH cheaper than DNA – and almost as accurate



Extensive genealogies – whakapapa – are a cost-effective option for disease risk estimation...

TE AO MĀORI / SCIENCE

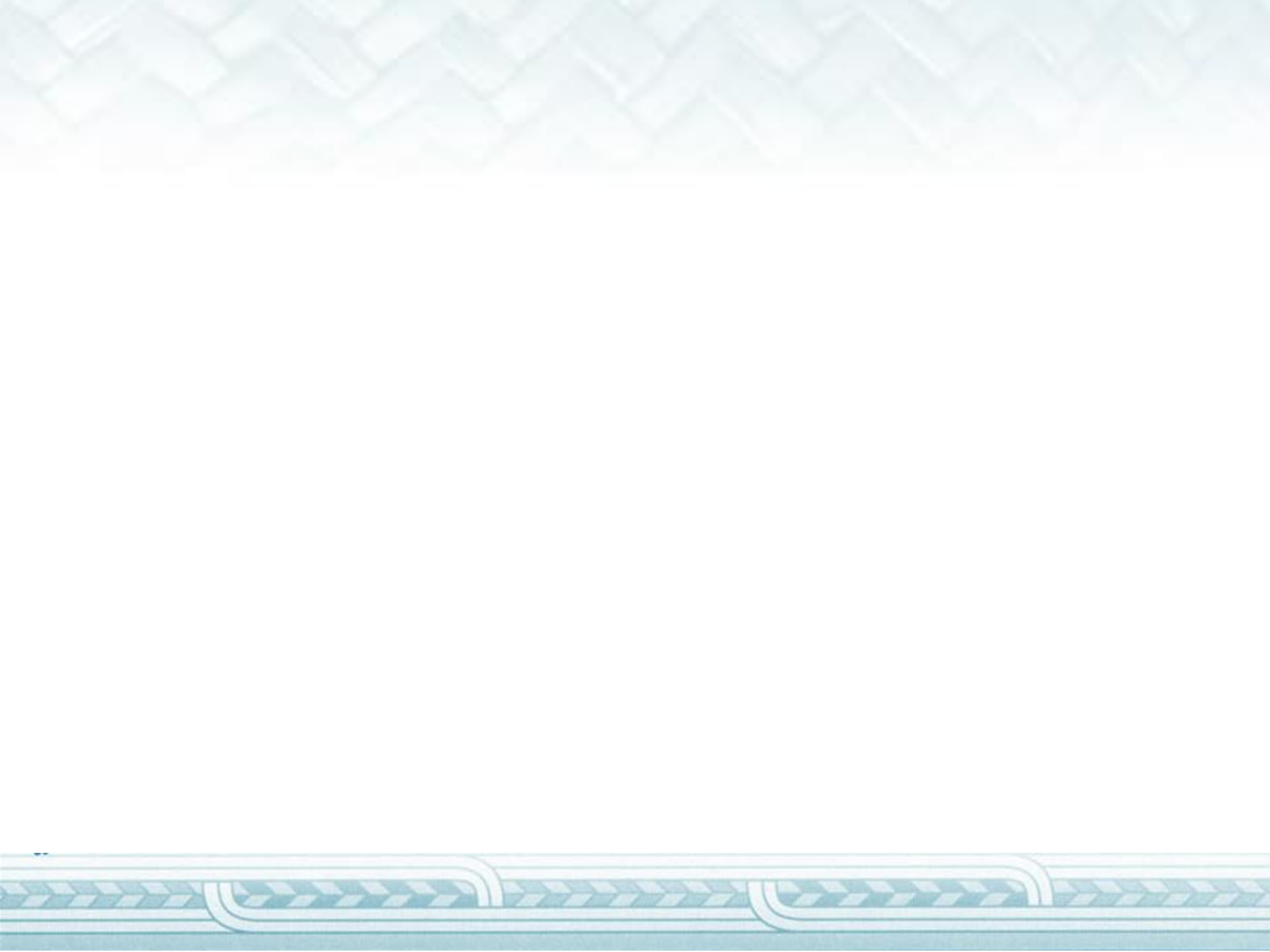
Is whakapapa the answer to better health treatment?

5:12 pm on 4 April 2025

Share this

Emma Andrews, Henare te Ua Māori Journalism Intern
emma.andrews@rmz.co.nz





Genomic Resources for Precision Health in Māori developed using Tikanga and Mātauranga Māori

1. He Kākano



He Kākano has already changed the diagnostic landscape

Prevent misdiagnosis and over-calling

- variants that look rare (and therefore suspicious) in European-dominant databases turn out to be *common and benign* in He Kākano

Increase diagnostic yield

- when a variant is genuinely rare within the correct ancestral context, we are more confident it is disease-causing

→ Leads to improved equity of access to genomic diagnosis

Clinicians and overseas laboratories asking about He Kākano



Journal of the Royal Society of New Zealand
Volume 35, Number 3, September, 2005, pp 215–227

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A values-based process for cross-cultural dialogue between scientists and Māori

P. L. Wilcox¹, J. A. Charity¹, M. R. Roberts^{1,2}, S. Tauwhare^{1,3}, B. Tipene-Matua^{1,2},
L. Kerrama-Royal^{1,4}, R. Hunter^{1,2}, H. M. Kan¹, P. Moke-Delaney^{1,2}

Abstract Cross-cultural dialogue is an essential part of the evaluation of controversial technologies and research proposals of significance to indigenous peoples. If Māori in Aotearoa/New Zealand are to benefit from these technologies it is important that effective processes are developed and implemented to ensure enduring outcomes for their communities. We describe a deliberate, multi-stage process to facilitate cross-cultural dialogue that starts well before research applications are submitted to funding and/or regulatory agencies. The process begins with provision of 'toolkits' to both the research provider and the Māori entities, which allows both to be better prepared to engage in constructive dialogue with each other concerning the proposal and its intended outcomes.



Te Mata Ira
Guidelines for Genomic
Research with Māori

Mr Maui Hudson
Dr Angela Beaton
Ms Mimi Mimi
Dr Waiara Puri
Prof Khyla Russell

Dr Barry Smith
Dr Valmaia Toki
Lyndy Gerrard
Dr Phil Wilcox



2. Rakeiora Computational Platform

Rakeiora: Data Analysis Platform

- Engaged NeSI to develop computational infrastructure to store and analyse data from both arms of study
- Infrastructure to be made available to researchers but implements principle of '*Māori control over Māori data*' and control over narratives arising



Implements data and algorithmic sovereignty....

Special issue: Precision medicine

Rakeiora Genomics Platform: a pathfinder for genomic medicine research in Aotearoa New Zealand

Claire E. Rye, Huti Puketapu-Watson, Helen Wihongi, Ben Te Aika, Donia Macartney-Coxson, Joep de Ligt, ...show all

Pages 2481-2505 | Received 14 Jun 2024, Accepted 13 Feb 2025, Published online: 24 Mar 2025

Cite this article

<https://doi.org/10.1080/03036758.2025.2469626>

Check for updates



Mātai Raraunga

Data analysis plan, provided by the approved researcher is interfaced to automated monitoring tools

Whakamarama.

Create transparency

Pono Whakaurunga

Remote monitoring tool which log, query, directions and responses between governance and researcher

Rārangi Whakatau

Decision log:- a register for senior researchers and Data Governors

Mana Whakahaere.

Remote permissioning tools

Mana Whakahaere Raraunga.

Data storage federation

Mana Rangatira

Decides appropriate sharing nationally and internationally

Control over the narrative

Scan tools for monitoring

Determines good and best practice

Closed ecosystem, with Maori decision making, including budget decision making

Mana Pukenga.

Genomic data analysis skills

Taumata Mana Pukenga

Adaptive standards of practice embedded into tools

Manaaki Tāngata/Tiaki Whakapapa

GP logging interventions against conditions to inform others and provide information to governance and cultural appropriateness.

GP and hauora need for access to large scale databases

Aroturuki Mana Whakatau

Measures of quality practice interfacing subjective decision making into machine learning delivery

Tiaki Whakapapa.

Discrete layer for indigenous metadata

Understanding inheritable risk prediction

Rangahau Tauwhāinga

Translational studies

Dr Helen Wihongi



Huti Watson



A/Prof Phillip Wilcox



Ben Te Aika



Figure 1. Tikanga attributes developed as part of Rakeiora, which were the central guide for every part of the Rakeiora Genomics Platform.

3. Māori PanGenome V1.0

Pangenome - SequenceTubeMap

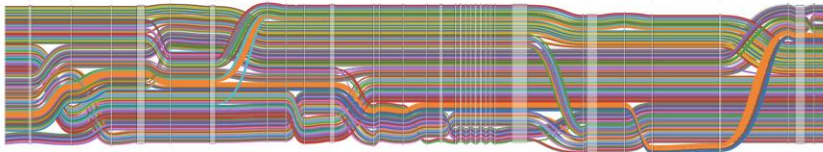


He Kākano Pangenome



HLA-A Part of Exon 2 (chr6:29,942,938-29,943,062)

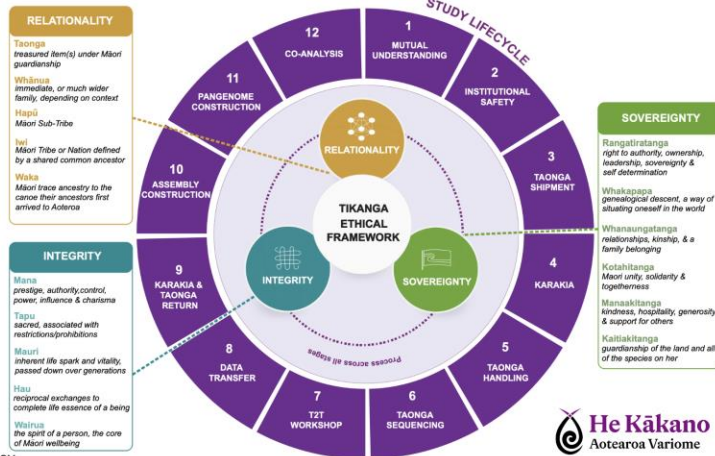
He Kākano + HPRC Pangenome



He Kākano + HPRC Pangenome



- Collaboration with UC Santa Cruz...
- Tikanga: tauutuutu (mutually uplifting reciprocity...)



Ann McCartney

'Knowledge Exchange' with Dr Karen Miga's Group at UCSC



UCSC -> Uni Otago

- Nanopore and HiC data generation
- Pangenome assembly experience
- <https://www.genomics-aotearoa.org.nz/news-and-events/advanced-genome-assembly-workshop>

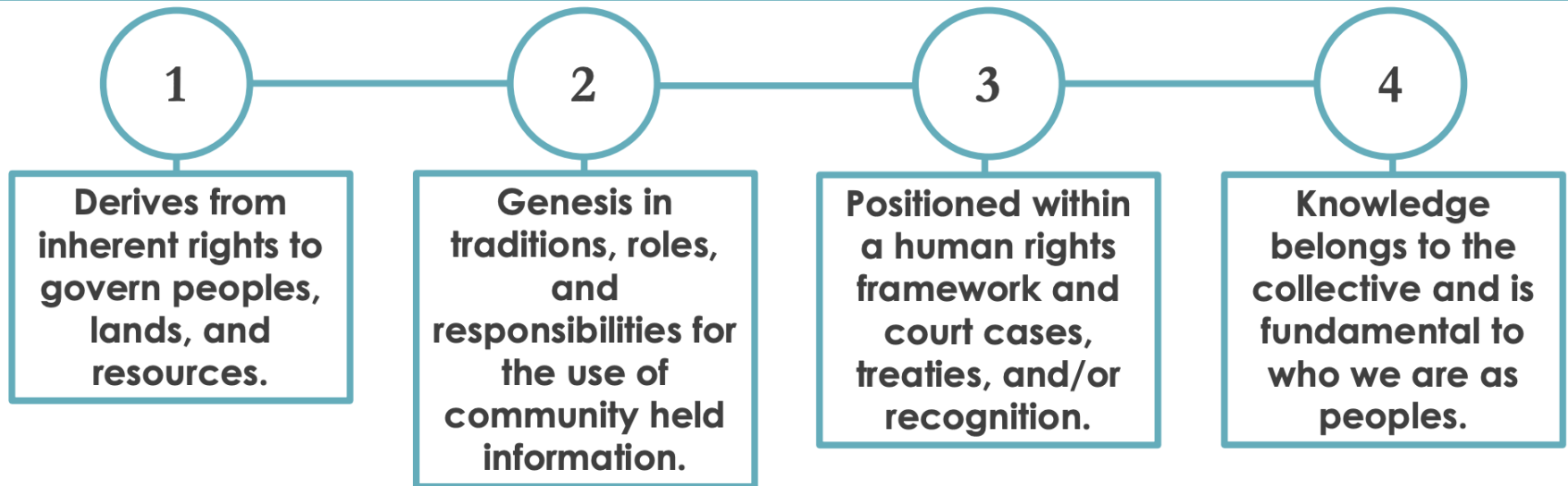
Uni Otago -> UCSC

- Frameworks for indigenous content in bioethics at UCSC



INDIGENOUS DATA SOVEREIGNTY

The *right* of Indigenous Peoples and nations to govern the collection, ownership, and application of their own data.



See Kukutai T & Taylor J. (Eds). (2016). Indigenous Data Sovereignty. Canberra: Australian National University Press.

[USINDIGENOUSDATA.ORG](https://usindigenoosdata.org) | [@USIDSN](https://twitter.com/USIDSN)

[GIDA-Global.ORG](https://gida-global.org) | [@GIDAGlobal](https://twitter.com/GIDAGlobal)

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The CARE Principles*

C = Collective Benefit: 'Data ecosystems shall be designed and function in ways that enable Indigenous Peoples to derive benefit from the data'

A = Authority to control: 'Indigenous Peoples rights and interests in indigenous data must be recognised and their authority to control such data be empowered. Indigenous data governance enables indigenous peoples and governing bodies to determine how Indigenous Peoples, as well as indigenous lands, territories, resources knowledges and geographical indicators, are indicated and identified within data.'

R = Responsibility: 'Those working with Indigenous data have a responsibility to share how those data are used to support Indigenous Peoples' self determination and collective benefit. Accountability requires meaningful and openly available evidence of these efforts and the benefits accruing to Indigenous Peoples.'

E = Ethics: 'Indigenous Peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.'

GIDA
Global Indigenous
Data Alliance

Promoting Indigenous Control of Indigenous Data

*Source: Global Indigenous Data Alliance

<https://www.gida-global.org/care>

DIGITAL TOOLS TO PROTECT INDIGENOUS DATA SOVEREIGNTY

- ✓ **Traditional Knowledge (TK) Labels.** Digital markers that define attribution, access, and use rights for Indigenous cultural heritage
- ✓ **Biocultural (BC) Labels.** Digital markers for provenance, transparency and integrity in research engagements related to community expectations and consent for use of collections and data.
- ✓ **Dynamic Consent Portal.** In Indigenous-led data repository to house Tribally-consented genomic sequence data and manage access and attribution.
- ✓ **Blockchain.** A distributed ledger system that tracks sharing via transactions, can fine-tune user access, attribute provenance, and facilitate data governance.
- ✓ **Federated learning.** To facilitate secure and community-consented data sharing.



Native **BioData**
consortium



Tikanga-Informed Genomic Data Governance Overview



Clare I. M. Adams
Irene Kereama-Royal
Phillip Wilcox

Tony Merriman
Megan Leask
Te Ira Tātai Whakaheke

Aotearoa Kahui @ Fonotaga Fa'asaenisi mo Togafitiga Talafeagai mo Tagata Polenisi



Waipapa
Taumata Rau
**University
of Auckland**



**University
of Otago**
ŌTĀKOU WHAKAIHU WAKA
NEW ZEALAND'S FIRST UNIVERSITY



MAURICE WILKINS CENTRE
FOR MOLECULAR BIODISCOVERY

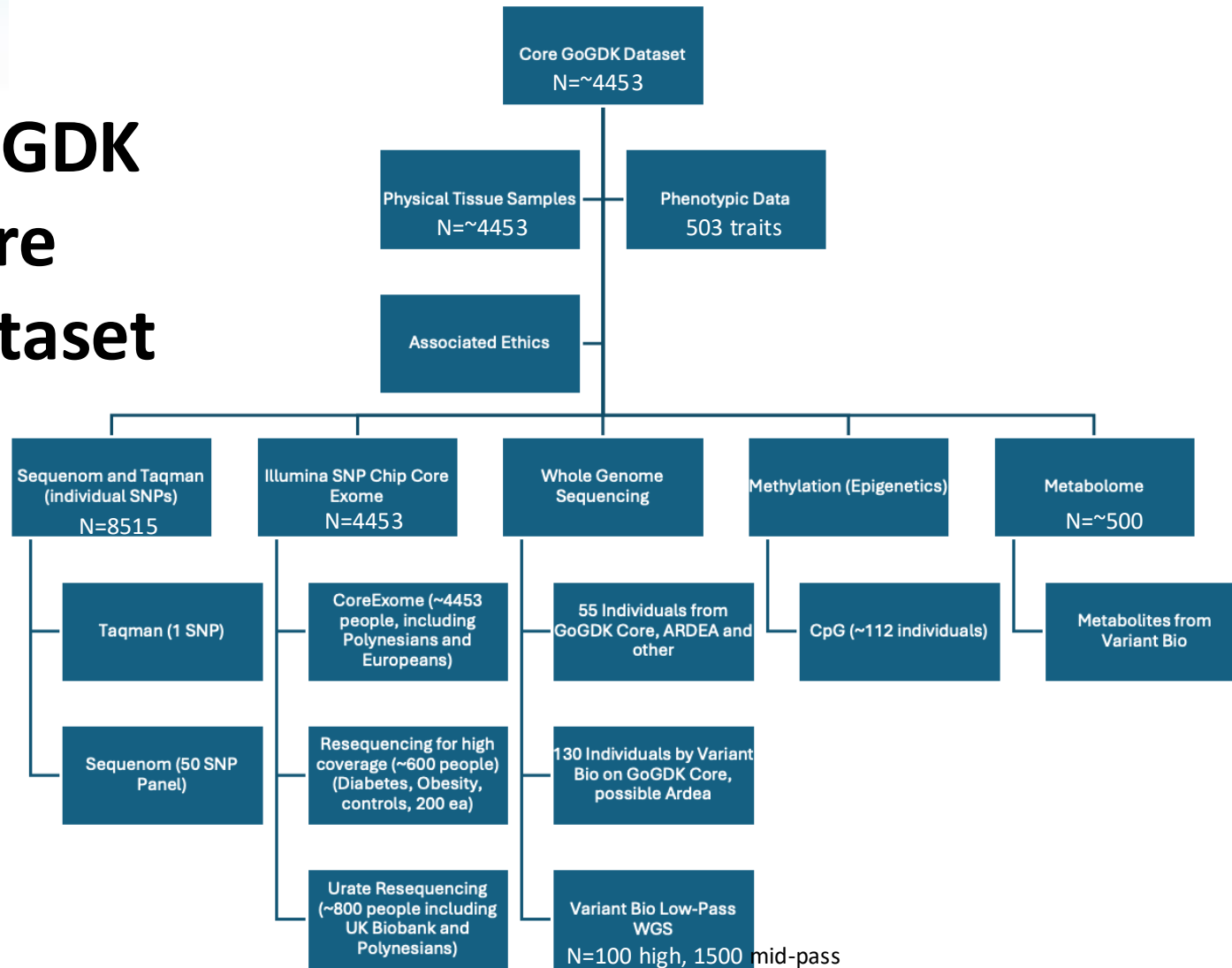


Ngati Porou Oranga



THE MOKO
foundation

GoGDK Core Dataset



Teams Involved:

GoGDK Team



Lisa Stamp



Tony Merriman



Janak de Zoysa



Nicola Dalbeth



Rinki Murphy

Te Ira Tātai Whakaheke



Ben Te Aika



Irene Kereama-Royal



Kimiora Henare



Phillip Wilcox



Helen Wihongi



Andrew Sporle



Huti Watson



Anna Rolleston

GoGDK Governance Pipeline – Why?

- Data are tikanga; data are taonga
- Taonga should be under Māori/community governance
- Driven by Tikanga and Kawa Māori
- Governance
 - Tikanga Māori values, kawa followed
 - Te Tiriti o Waitangi-based partnership
 - Indigenous data sovereignty principles



ITW and Researchers gathered to talk,
January 2025

Rightsholders

Data Authority

Community obligations

Trusted relationship holders

Stakeholders

Constructed dataset

Use, engage with dataset

Principal Investigators

Proposed Governance Rōpū

Group	Category	Represented by	Proposed Number of Representatives
Principal Scientific Investigators / Researchers	Stakeholder	Previous PIs to GoGDK-related projects	≥2 to examine scientific validity (clinical, genetics) AND ethical, privacy, prior track record and reputation regarding data sharing/access to the data.
Māori: Ngāti Porou Oranga	Primary Rightsholder	Ngāti Porou Oranga	1-2
Māori ki Aotearoa	Primary Rightsholder	Te Ira Tātai Whakaheke	2-4
Pukapuka	Rightsholder	Mandated Community	1
Non-Aotearoa Polynesian	Rightsholder	Selected from Pacific Leadership Forum (Irene Kereama-Royal)	2-3

Pipeline for Access and Use

Irene Kereama-
Royal



STAKEHOLDER OPERATIONS (Research Users)

