

# The NETwork! Roadmap for Genomic Research and Māori Engagement in New Zealand

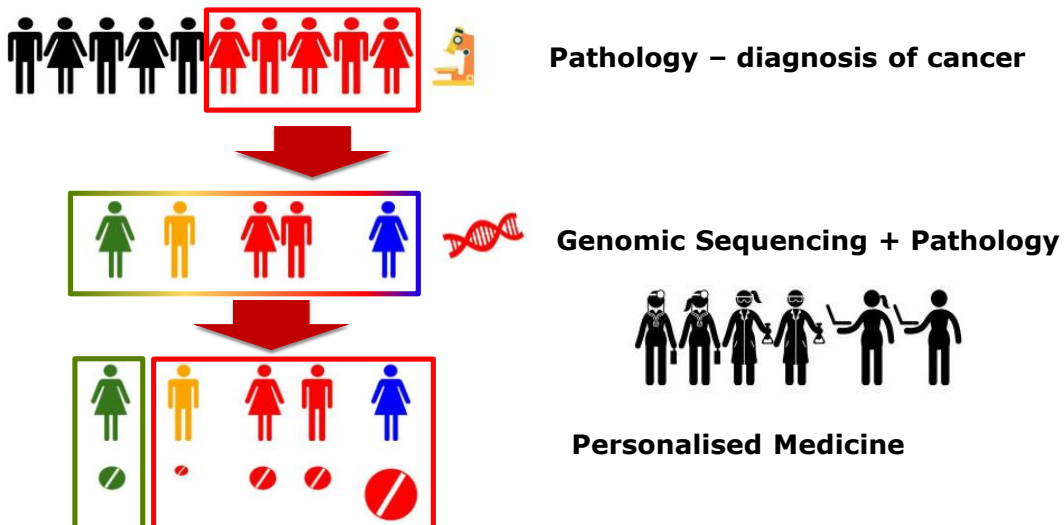
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## Genomic Technology & Personalised Cancer Medicine



# Protection, Partnership, Participation



## 'Signing of the Treaty of Waitangi'

**February 6, 1840**

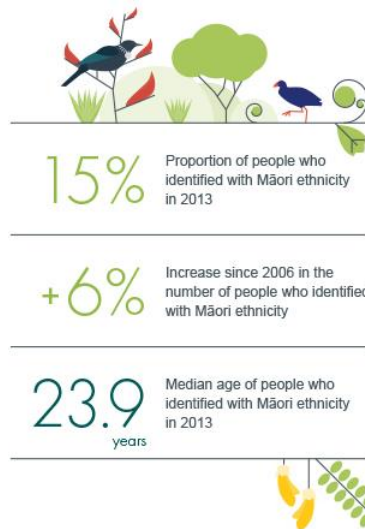
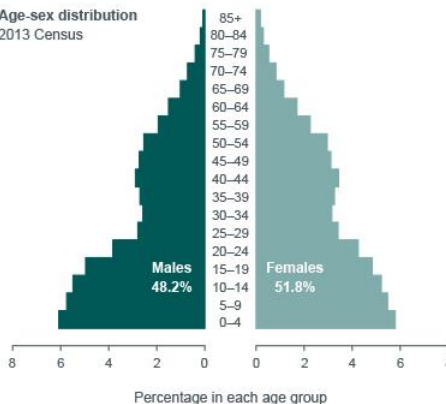
Modern reconstruction, showing Tāmāti Wāka Nene signing the Treaty in front of James Busby, Captain William Hobson and other British officials and witnesses. Some Māori signatories are assembled on the left.

By Marcus King (artist)  
Ref: G-821-2  
Alexander Turnbull Library

## Māori population in New Zealand

### Māori

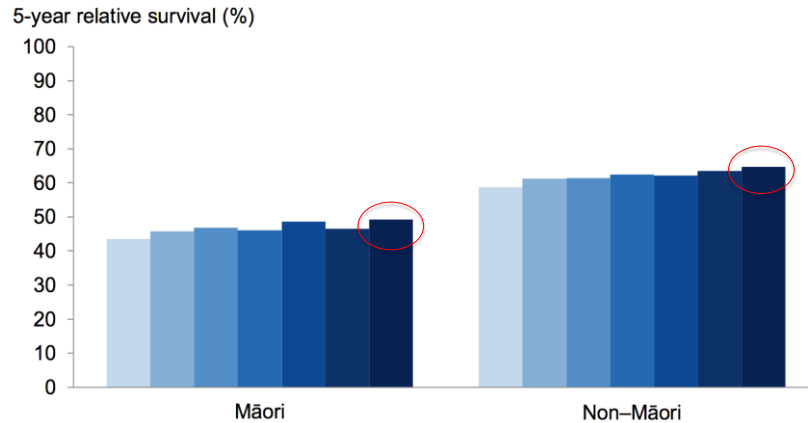
Age-sex distribution  
2013 Census



Source: [Statistics New Zealand](http://www.stats.govt.nz) and licensed by Statistics NZ for re-use under the [Creative Commons Attribution 4.0 International](https://creativecommons.org/licenses/by/4.0/) licence.

# Equitable?

## Survival, by ethnic group



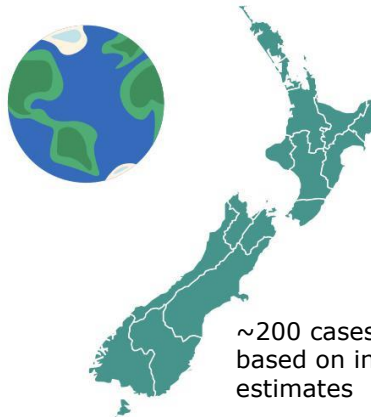
# Neuroendocrine Tumours (NETs)

Uncommon, slow-growing tumours that develop from hormone secreting cells

New Zealand incidence not known

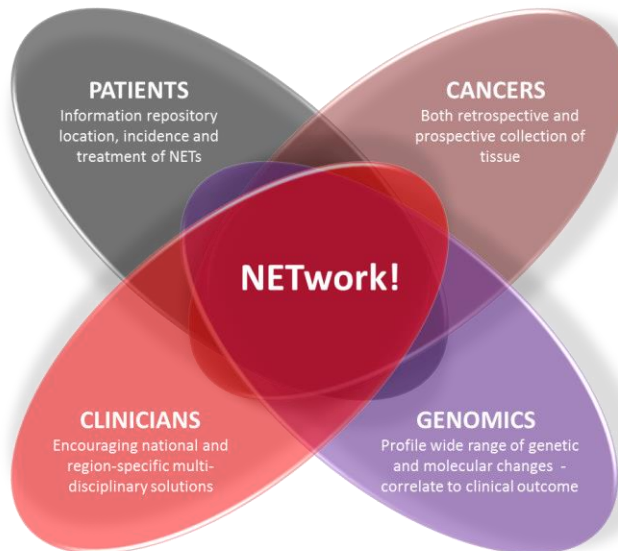


- GI tract
- Lungs
- Pancreas
- Ovaries/Testes



~200 cases per year  
based on international  
estimates

## PUKUmahi! or NETwork! is a multifaceted project.



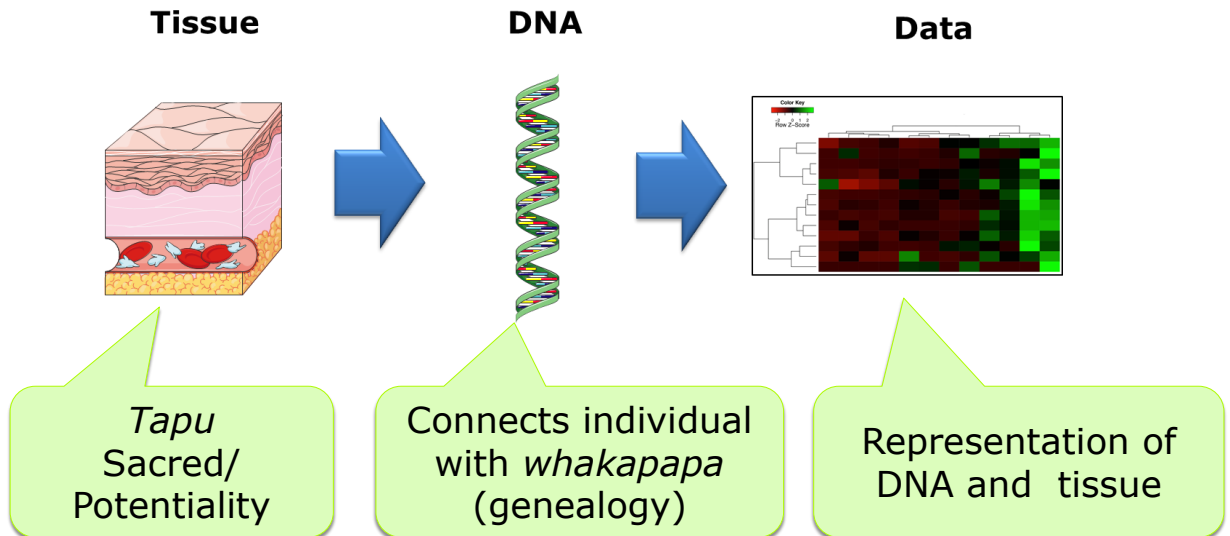
### PUKUmahi:

- *puku* (tumour)
- *mahi* (work)
- *pukumahi* (industrious, hardworking, diligent)

## Kaupapa – Purpose/Intentions

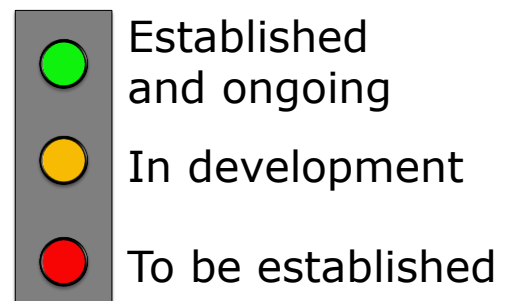
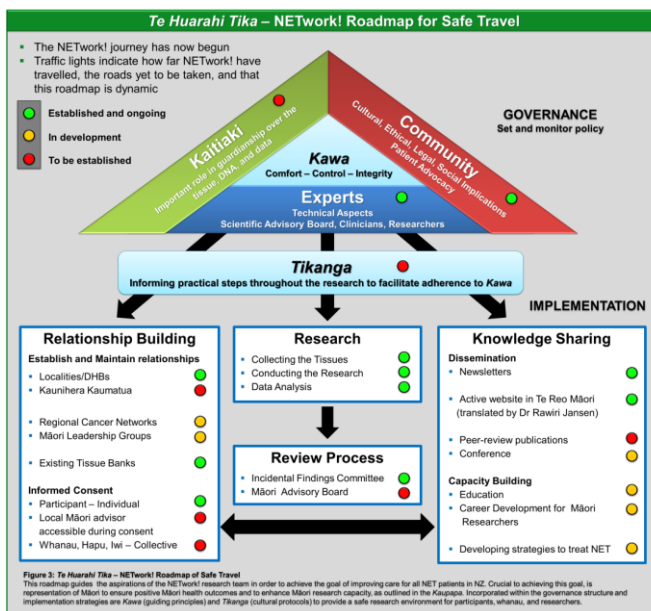
- **Nationwide research** that will involve Māori and relates directly to Māori health.
- Urgent need for
  - **Positive Māori health outcomes**
  - **Enhancing Māori research capacity**
- Ensuring that PUKUmahi! has **sufficient representation of Māori to benefit Māori health**
- Ensure **culturally safe research environment**
- **Minimize the potential of repeating past transgressions**
  - Arizona State University
  - The 'warrior gene' hypothesis

# Tissue is precious... and so is the Data



"Tissue" and "DNA" Servier Medical Art provided by Servier under [CC BY 3.0](https://creativecommons.org/licenses/by/3.0/)

## The NETwork! Roadmap for Safe Travel (v1.0)



# NETwork! Governance Structure

Set and monitor policy

## **Kawa – Guiding Principles**

***Comfort – for Participants, Whanau, and Researchers***

***Control – Consent process***

***Integrity – sticking to what was consented/agreed***

## Tikanga – Cultural Protocols

### ***Tikanga***

**Informing practical steps incorporated throughout the research to facilitate adherence to *Kawa***

***Tikanga should inform:***

#### Tissue collection & disposal

Karakia (blessing)  
Respect spiritual elements  
and whakapapa  
Closure/Peace

#### Community engagement

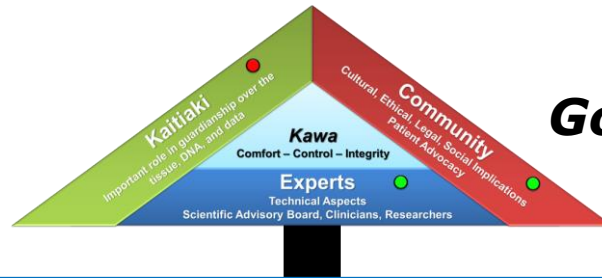
Cultural Safety and  
Sensitivity

**Reciprocity**

#### Use of samples and data

Accepting and maintaining  
responsibility

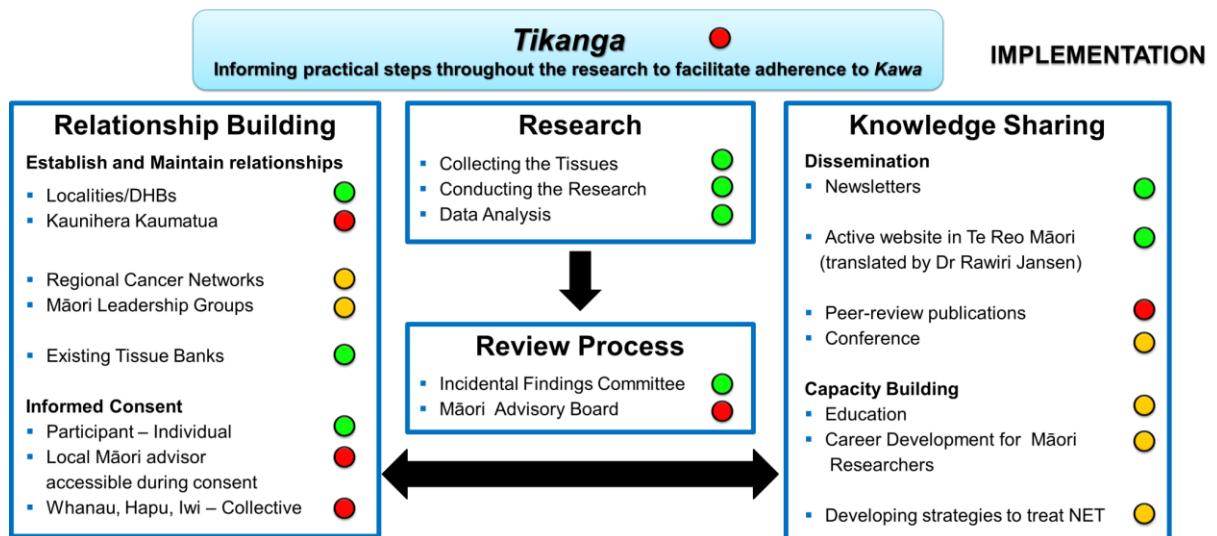
## Governance



## Tikanga

Informing practical steps throughout the research to facilitate adherence to *Kawa*

## Implementation



# Whakarāpopototanga (Summary)

- Personalised Medicine for Cancer is coming and is going to involve Genomic Technology
- We need to establish culturally safe practices in this context to ensure that health benefits extend to Māori (and indigenous people)
- The NETwork Roadmap v1.0 is a dynamic roadmap guiding the researchers and clinicians on best practice to address these challenges

## Nga mihi - Acknowledgements



**MEDICAL AND  
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Prof. Michael Findlay  
Dr Kate Parker



Assoc/Prof. Papaarangi Reid, Tumuaki



**MEDICAL AND  
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Auckland Medical  
Research Foundation  
est. 1955

### Te Mata Ira

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