Data, difference, and an indigenous development dividend to big data health analytics

CoMPASS Symposium. Tāmaki Campus. June 2018.

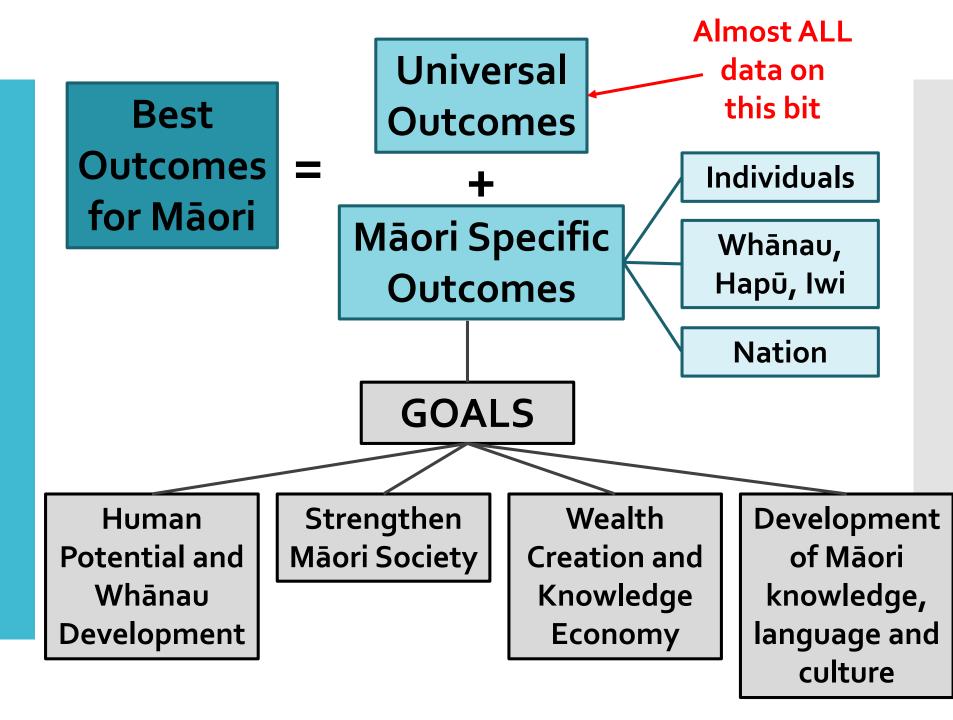


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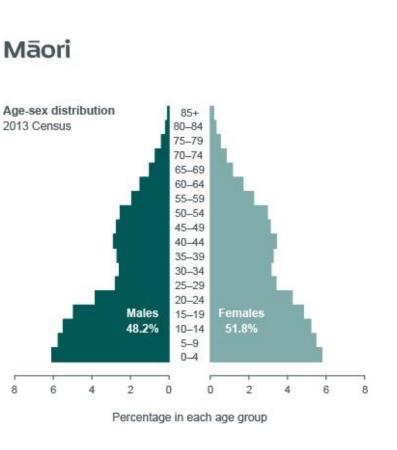
Andrew Sporle

Māori Development Goals

(Durie MH 2003)

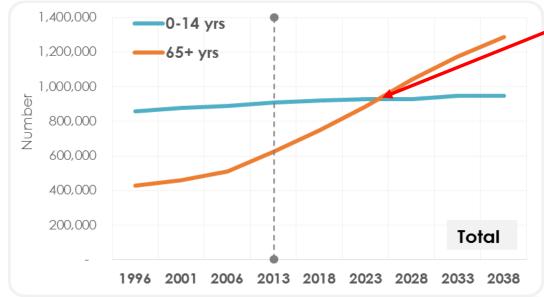


'Potential' demographic dividend in a Post-Settlement Context





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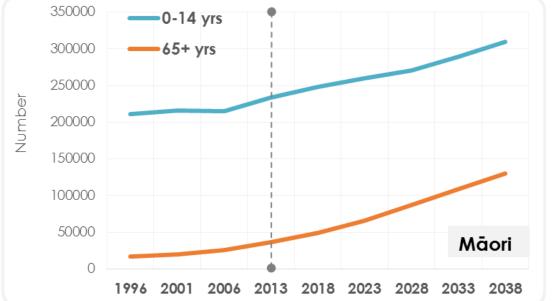




Opportunity for major impact of lifecourse and inter-generational research

More older people

than kids

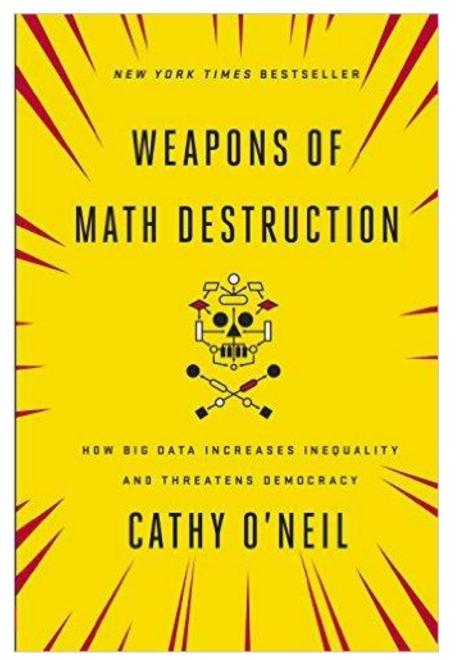


Data is a social product – and so is analysis

Imperfect data, imperfect models, embedded values can create self-fulfilling feedback loops.





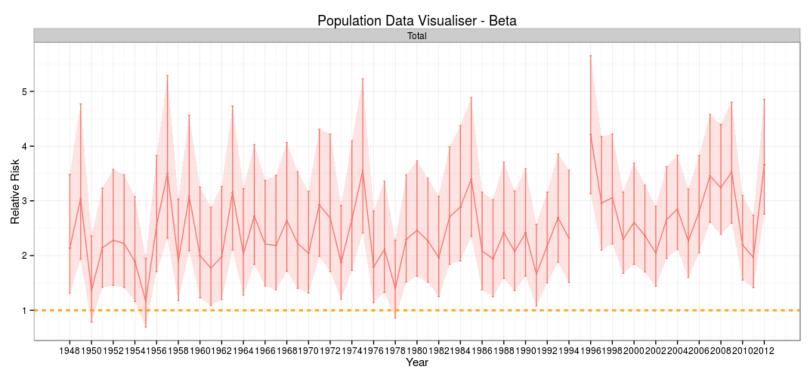


"big data increases inequality and threatens democracy."

Can deficit data, accessible by a few, inform development?

Starting point: transparency and engagement

Data and Inequality of Outcomes



Stomach Cancer Death
Trend uncertain
Māori rates 3.7 times higher
than non-Māori

Māori/ Non-Māori relative risk for stomach cancer incidence 1963-2012

Standardised to Māori population

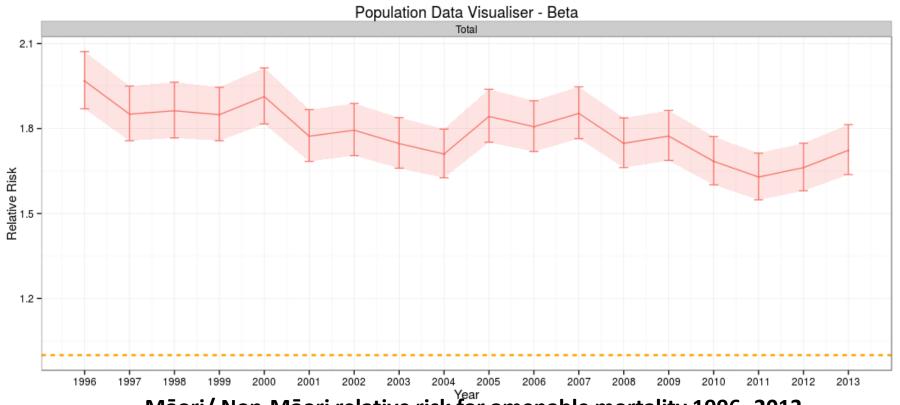
Source: DoH and MoH Mortality collection data via Data Visualiser





Outcome monitoring necessary but not sufficient

Data and Inequitable Impact



Amenable Mortality (MoH) Slow decrease. Māori rates 1.7 times higher than non-Māori

Ambulatory sensitive hospitalisation rate M/nMRR = 1.6

Māori/ Non-Māori relative risk for amenable mortality 1996 -2013

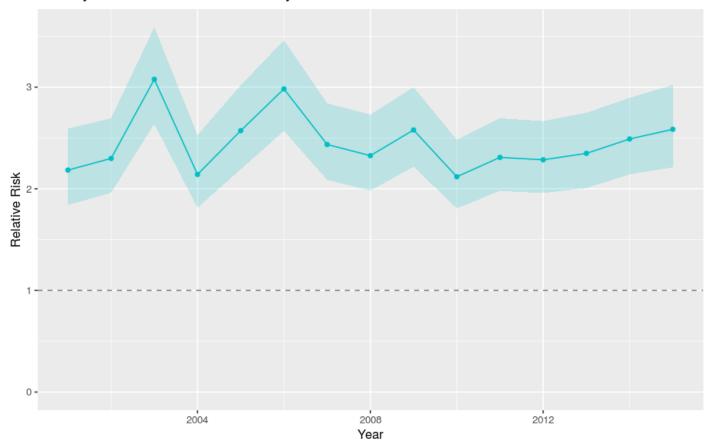
Standardised to Māori population

Source: DoH and MoH Mortality collection data via Data Visualiser

SCIENCE DEPARTMENT OF STATISTICS **Identifying intervention points**

Data and Inequitable Impact

Ministry of Health Amenable Mortality Relative Risk



Amenable Mortality (MoH)

Population

Maori Total (Counties Manukau)

Regional variation in service impact for Māori

Identifying intervention location



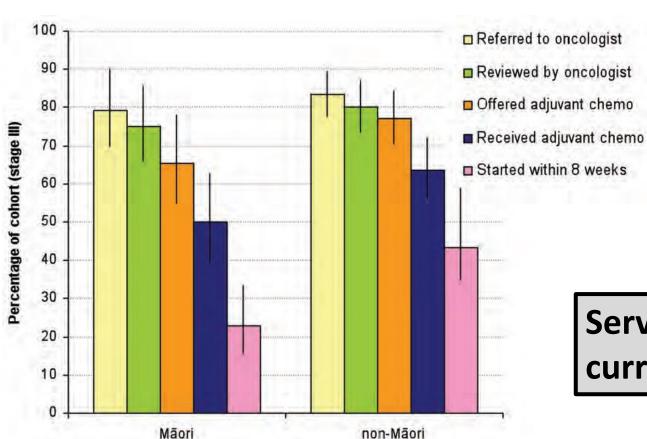
Māori/ Non-Māori relative risk for amenable mortality 1996 -2015

Standardised to WHO population

Source: DoH and MoH Mortality collection data via Data Visualiser



Data and Identifying Inequitable Processes?



Inequalities in colon cancer survival between Māori and non-Māori arise due to <u>lots of small</u> <u>differences</u> cumulating

Service delivery process review is currently ad-hoc and research funded



Sources: Hill S, Sarfati D, Blakely T, et al. Ethnicity and management of colon cancer in New Zealand. Cancer 2010;116(13):3205-14. Hill S, Sarfati D, Blakely T, et al. Survival disparities in Indigenous and non-Indigenous New Zealanders with colon cancer. J Epidemiol Comm Health 2010;64(2):117-23.

Issues with current Data resources for Māori Development

Require descent and tribal information

Availability of Māori - defined measures

Deficit or development measures

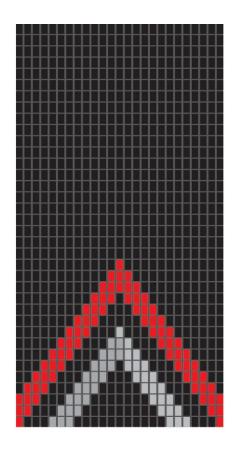
Census link can provide these BUT:

- Census participation varies by ethnicity, gender and age
- Matching not complete?similar variation
- Iwi list not comprehensive
- Iwi data quality?

PRECISION – more important for smaller populations

"Tribes must grapple with the task of building strong nations while utilising data that have been collected to advance the aims of other governments."

Desi Rodriquez-Lonebear



TE MANA RARAUNGA

Māori Data Sovereignty Network

"He whenua hou,
Te Ao Raraunga,
Te Ao Raraunga,
He whenua hou"

Kirikowhai Mikaere

(Data is the new land)

Data is a valuable strategic resource

https://www.temanararaunga.maori.nz/

Māori Development Parameters (some)

Māori as data providers

Engagement with Māori

Statutory protections and independence

Consultation with Māori

Protecting Māori interests Transparent methods

Individual and Collective measures

Co-design

Maintaining
Social and
Cultural
licence

Māori determined content

Ownership and use resolved

Co-collection

Māori methodology Māori capacity building

Data Initiatives and Māori Development

Māori Development parameters (some)		Provider Data	IDI	
Māori as data providers		✓	✓	
Engagement with Māori			\checkmark	
Consultation with Māori			✓	
Ownership and use resolved	Risks			
Co-design	 Māori development dividend Data system backlash "It's not for us, it's about us" 			
Co-collection				
Statutory protections and independence				
Transparent methods				
Māori methodology		•		
Protecting Māori interests				
Maintaining Social and Cultural licence				
Māori capacity building				



Māori driven community development

Focus areas >

Opportunities >

Solutions >

EDUCATION

- Increase Numeracy & Literacy attainment
- Increase school leavers attaining NCEA Level 2 or above
- Ruapehu Learning Journal
- Whānau Reading, Literacy & Numeracy Programme
- 3. Community Tagging
- 4. NCEA & Whanau

EMPLOYMENT

- Connect local jobs & local workers
- Local workforce has the right capacity
- 5. Community Work Broker
- 6. Community Careers Expo
- 7. Trades Training
- 8. Local Skill Needs Analysis
- Community Learning
 Centre

HOUSING

- Increase available houses to rent
- Increase % of healthy homes
- 10. Housing Needs survey and Action Plan
- 11. Sponsored Home Ownership programme
- 12. Healthy Homes Initiative
- 13. Property WOF
- Research alternative housing developments

HEALTH

- Increase availability & access to local services
- Collaborate across service providers
- 15. Hauora Navigator
- 16. Wellbeing Expo
- 17. Hauora Yellow Pages
- 18. Integrated Service Centre

 a one stop shop

SOCIAL

- Stronger whanau
- Connected, Cohesive, Collaborating Communities
- 19. Ruapehu TopTown
- Extend Kattoko Whānau programme.
- Community Values (Maunga, Tangata, Tukotahi)
- 22. Community technology hub
- 23. Street by street initiative

Our Purpose >

To enable whānau transformation in the Ruapehu rohe



More progress for Te Hiku Social Accord for iwi in Far North

26 Jun, 2018 10:00am 3 minutes to read



Nanaia Mahuta greeting Te Hiku iwi leader Haami Piripi to Wellington. Photo / Supplied

Northland Age

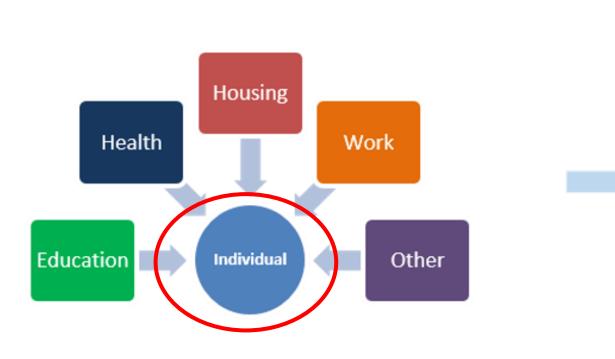
Far North Iwi leaders met with key Cabinet Ministers in Wellington on Thursday, to outline their priorities and aspirations and to advance partnership initiatives under the Te Hiku Social Accord.

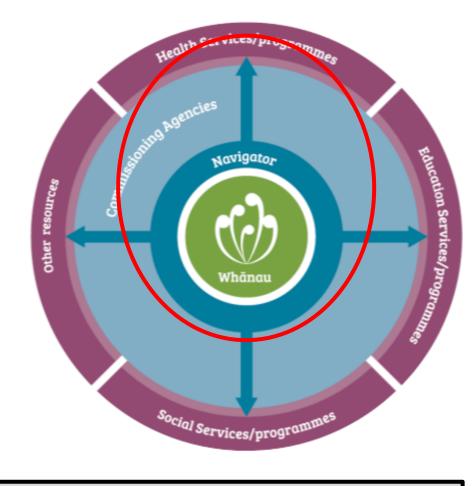
The Accord, negotiated as part of the Te Hiku iwi Treaty settlement legislation, is founded on the vision of cultural, social and economic prosperity for the communities, whānau, hapū and iwi of Te Hiku, last week being the first opportunity for iwi to meet with the new set of government ministers to review the progress that has been made so far, and to build on the strategic approach provided by the Accord.

"Many of our Māori whānau are still in a crisis situation in terms of safety, housing, education and employment," Te Hiku iwi leader Haami Piripi said.

"Our iwi have been working hard with agencies to fully understand the current state of wellbeing of our whānau of Te Hiku, and it's not a pretty picture.

Whanau Ora embeds Māori values





Improved health care access
BUT

in the context of Māori definition of individual and whanau wellbeing

Needs:

- Different data
- Different concepts (SES, Lifecourse)

Building Māori data capability and capacity



Māori GIS project

Iwi Statistical Standard Review

Local Māori Data Needs

Māori longitudinal capability within the OSS

Data system responsiveness

Data Visualisation

Workforce development

Māori data capability

Creating triballydefined geographic boundaries for **Official Data**



Official data sources are organized around central and local government boundaries.

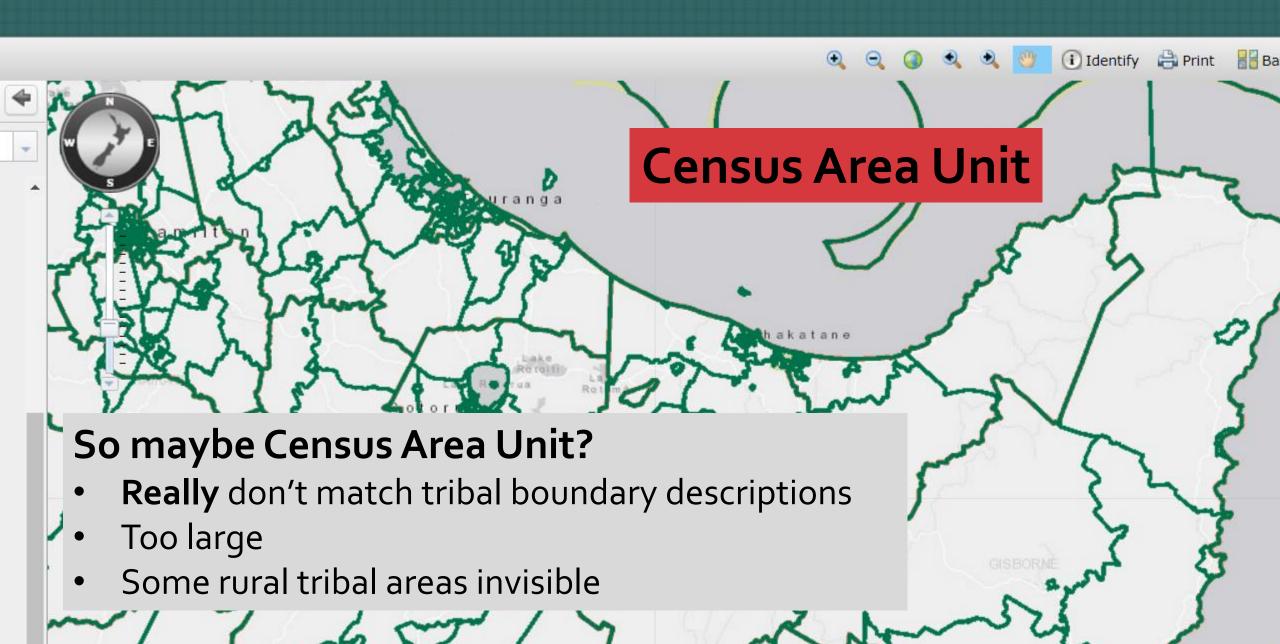
Can official data be organised around Māori governance areas?

Official statistics existing structure:

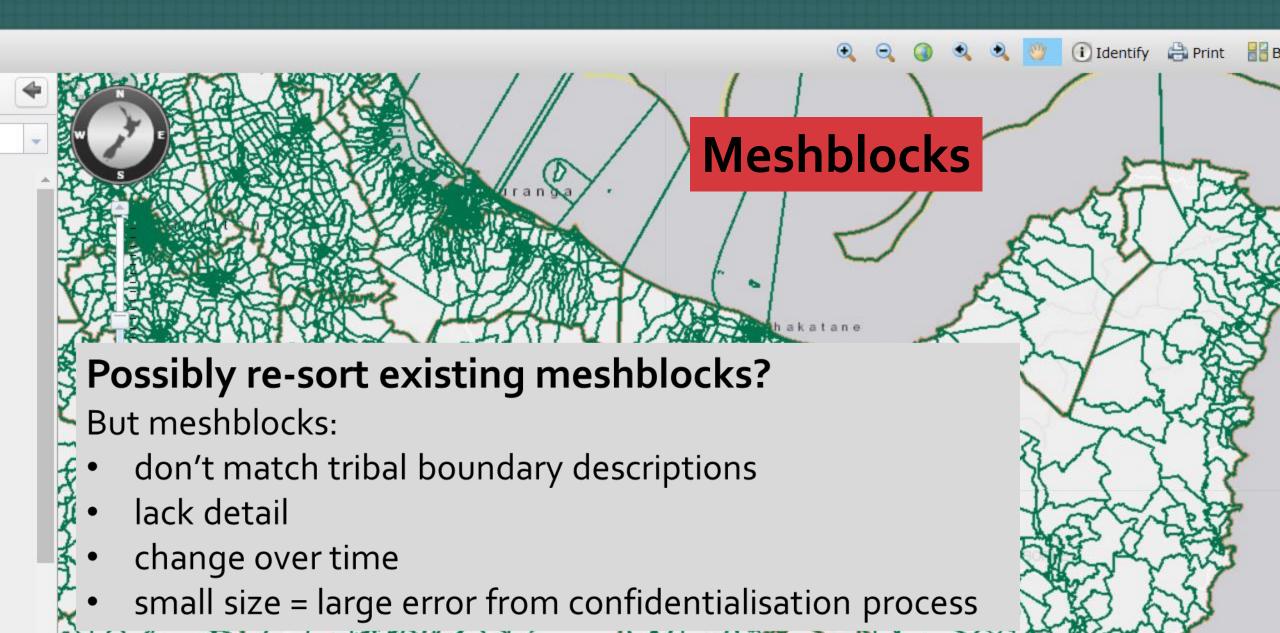
- Meshblocks
 - Smallest area data building block
 - ~ 40 households (~ 100 people)
- Census area units (made up of meshblocks)
 - Smallest area routinely accessible





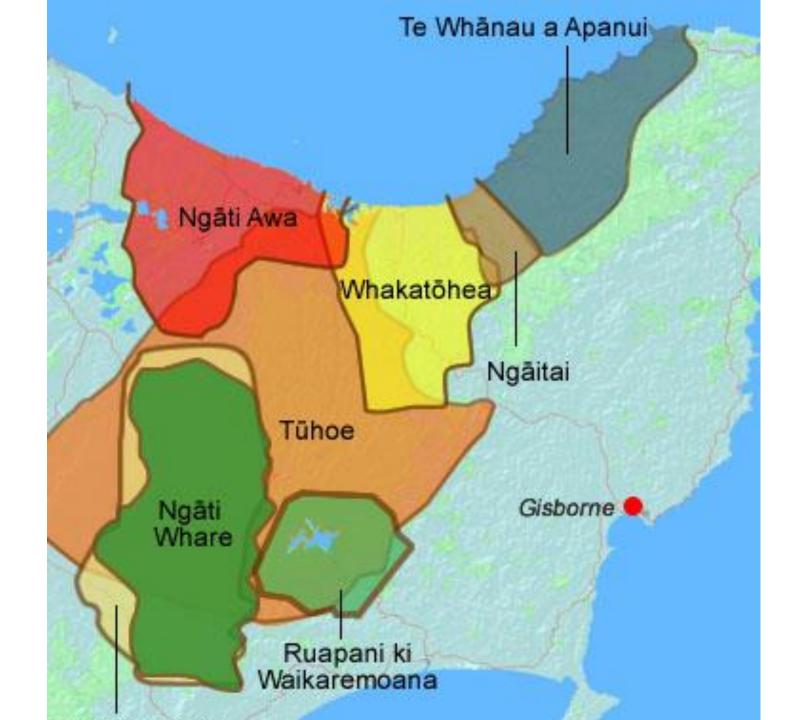




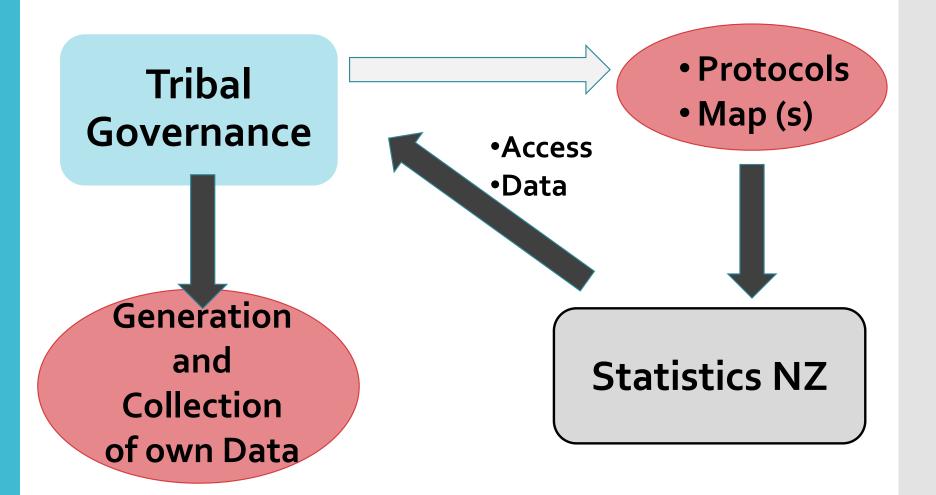


A Māori GIS capability to the Official **Statistics System** A permanent structural change





Changing the Map: Making data local



Transform **Data Use**

□ SHARE

A Locally Based Initiative to Support People and Communities by Transformative Use of Data

JULIA LANE, DAVID C. KENDRICK, DAVID T. ELLWOOD

The data revolution is transforming how executives manage operations and businesses deliver goods and services. Yet when it comes to helping people escape poverty, the revolution has barely begun.

DOWNLOAD THIS PAPER

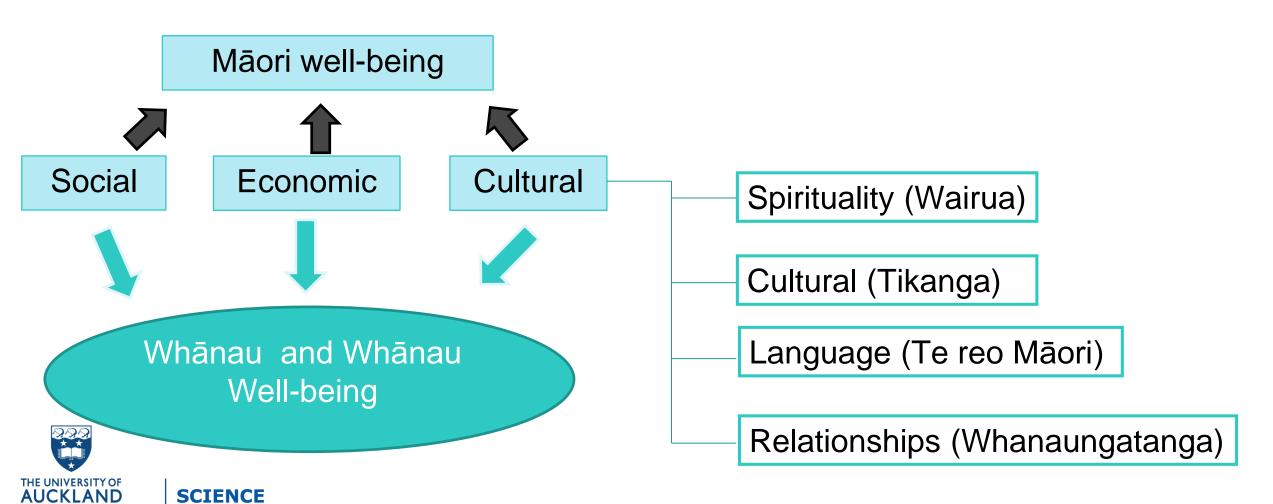
Full Idea Paper

Summary >

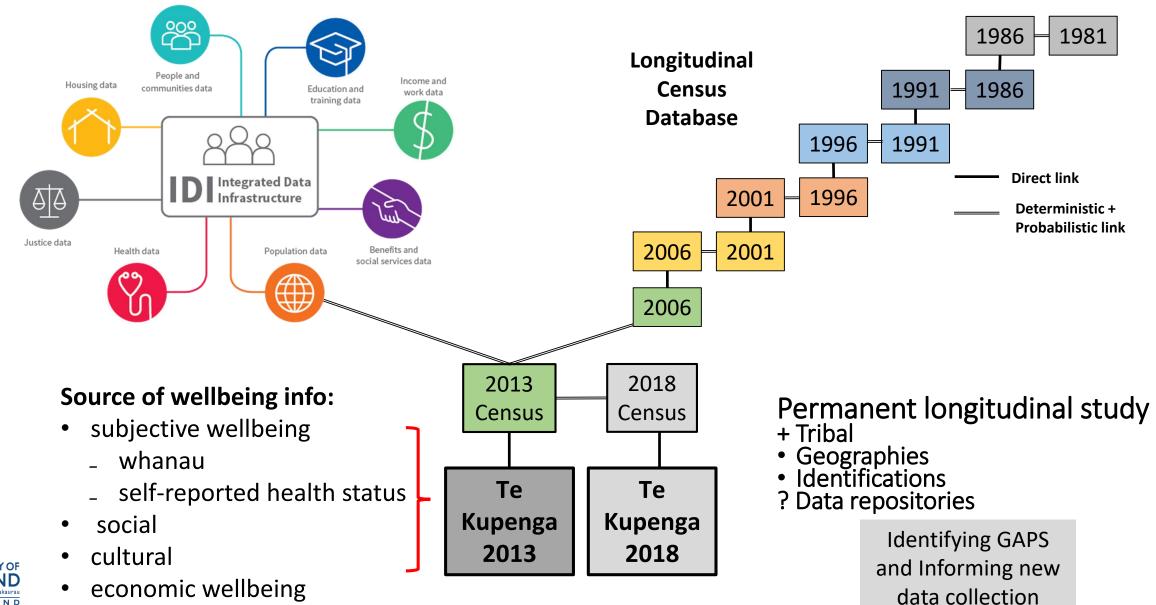
Te Kupenga 2013 survey – what's new about it?

Statistics NZ's first survey of Māori well-being.

DEPARTMENT OF STATISTICS



Te Hao Nui - Māori longitudinal capacity in the OSS





Re-orientating the Data System to inform Development



Combined commitment to change

Māori Specific Outcomes:

Supporting locally driven innovation to match need

Universal Outcomes:
Data system monitoring
of local and national
inequity

Changing

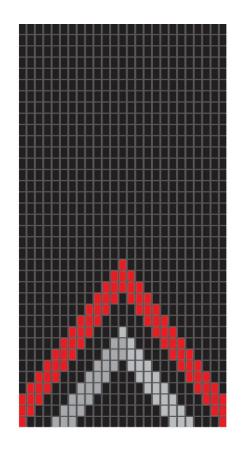
What is measured Who can access it How it is accessed How it is analysed

Māori data capability

- Workforce
- Technology



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TE MANA RARAUNGA

Advocating for the development of capacity and capability across the Māori data ecosystem including:

- Data rights and interests
- Data governance
- Data storage and security
- Data access and control

https://www.temanararaunga.maori.nz/

Māori Data Sovereignty Network