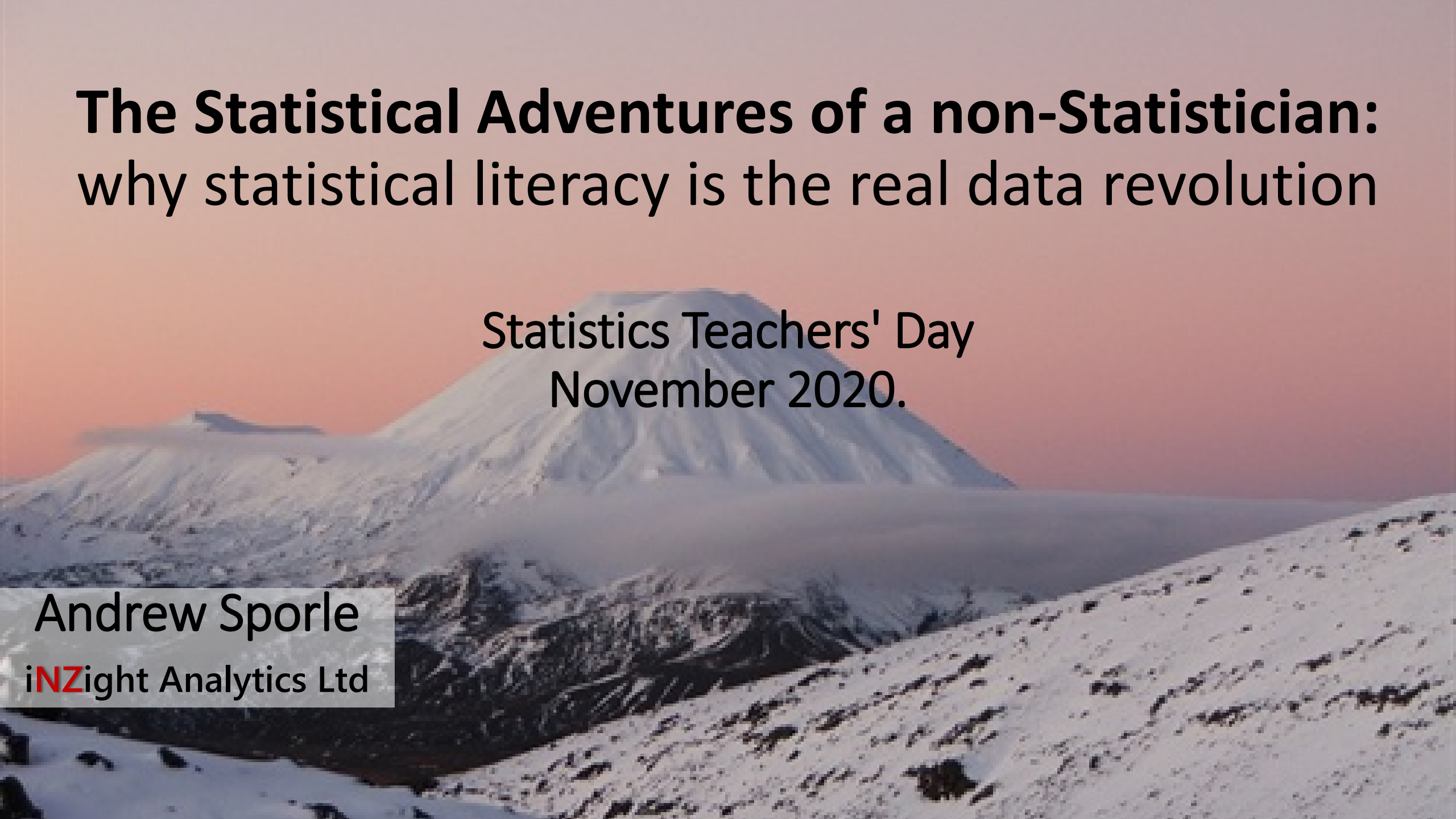
The Statistical Adventures of a non-Statistician: why statistical literacy is the real data revolution

Statistics Teachers' Day
November 2020.



Andrew Sporle
iNZight Analytics Ltd

Epidemiology in Aotearoa New Zealand – Te Timatanga

Te Rangi Hiroa – Sir Peter Buck (Ngati Mutunga)

First Māori doctor to graduate in NZ
Young Māori Party – political change

First modern style epidemiological article in Aotearoa NZ (1914)

(cited in Pool DI 1991 and 2015)

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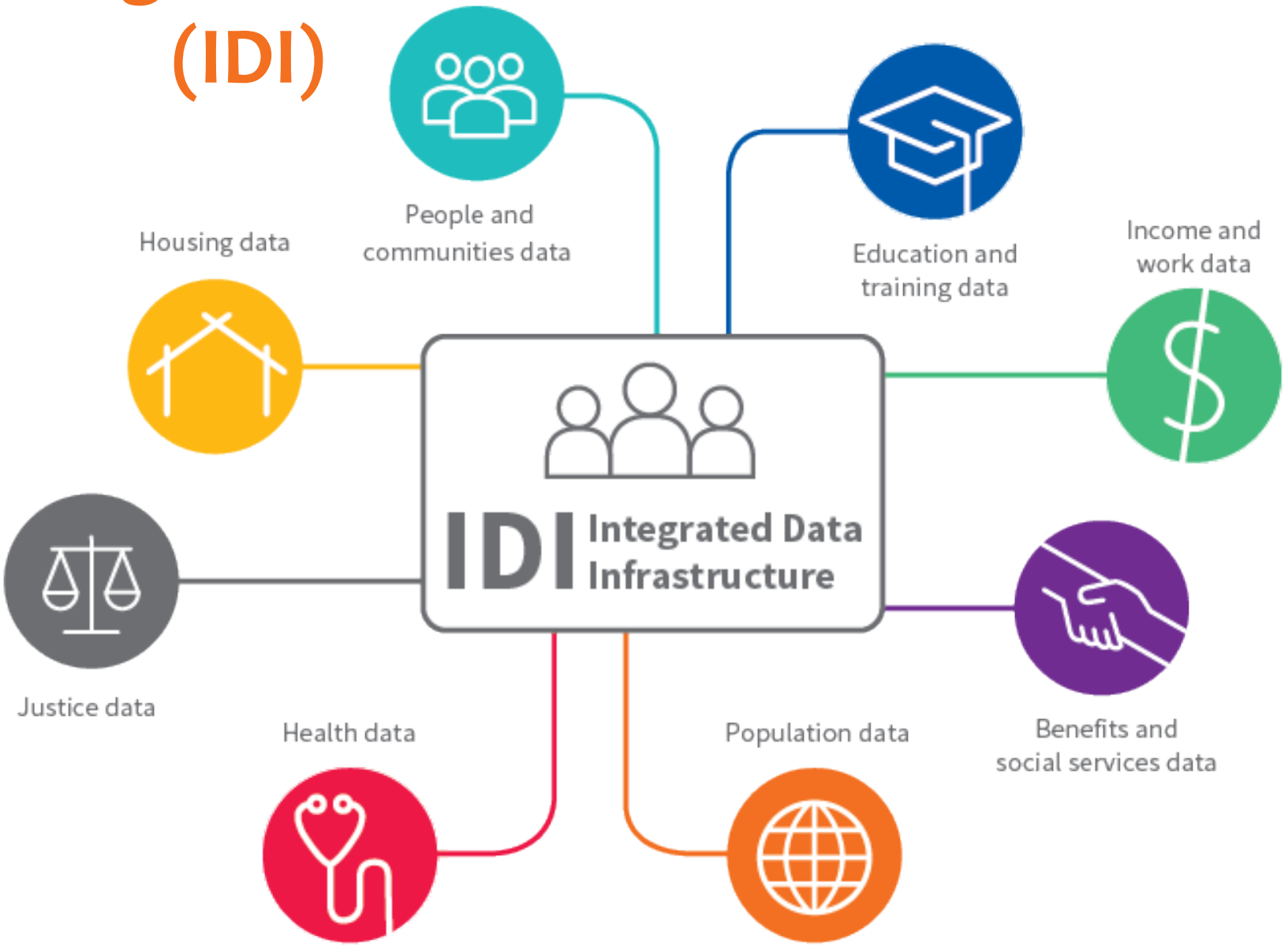
New Zealand's Integrated Data Infrastructure (IDI)

An integrated database

containing de-identified longitudinal microdata

about

people, households, & businesses.

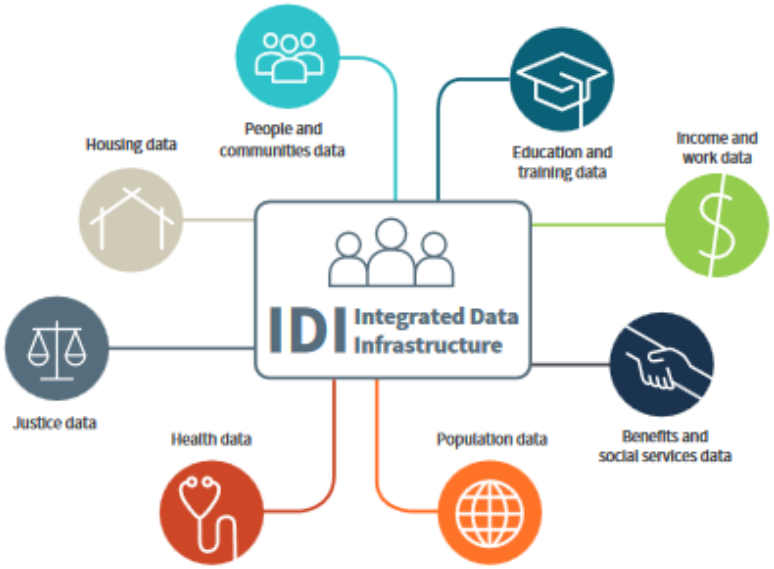


For a full list of data, go to www.stats.govt.nz/idi

Data in the IDI September 2018

Stats NZ Tatauranga Aotearoa

Stats NZ's Integrated Data Infrastructure (IDI) is a large research database containing de-identified microdata about people and households.



The IDI contains person-centred microdata from a range of government agencies, Stats NZ surveys including the 2013 Census, and non-government organisations. For more information about data in the IDI, see **www.stats.govt.nz/integrated-data/integrated-data-infrastructure**

The Longitudinal Business Database (LBD) complements the IDI with microdata about businesses. For more information about data in the LBD, see **www.stats.govt.nz/integrated-data/longitudinal-business-database**

Health

Health data
- B4 School Checks – from 2011
- Cancer registrations – from 1995
- Chronic conditions – from 2007
- General medical services claims – from 2002
- Health tracker – 2006-13
- Laboratory claims – from 2003
- Mortality – from 1988
- Immunisation – from 2006
- National non-admitted patient collection – from 2007
- Pharmaceuticals – from 2005
- PHO enrolments – from 2003
- Population cohort demographics and addresses – from 2004
- Mental health and addiction – from 2008
- Publicly funded hospital discharges – from 1988
- National Needs Assessment and Service Coordination Information System (SOCRATES)
- Maternity – from 2003

Education

Education and training data
- Early childhood education participation
- Primary education – from 2007
- Secondary education – from 2004
- Tertiary education – from 1994
- Industry training – from 2001
- Targeted training – from 2001
- Adult competency assessments – from 2014

Benefits / Social services

Benefits and social
- Benefits – from 1990
- Youth services – from
- Children's Action Plan – from 1996
- Working for Families – from 2003
- Child, Youth, and Family – from 1991
- Student loans and allowances – fr
- ACC injury claims – from 1994
- Family Start – from 2008

Student loans

Justice

Justice data
- Recorded crime: offenders – from 2009
- Recorded crime: victims – from 2014
- Court charges – from 1992
- Sentencing and remand – from 1998

Community

People and communities dat
- Auckland City Mission – from 19
- Migrant Survey – from 2012
- Driver licence and motor vehicle registers
- Longitudinal Immigration Survey of NZ – 2005-09
- General Social Survey – 2008-2016
- Disability Survey – 2013
- Te Kupenga – 2013

Travel / Migration

Population data
- Border movements – from 1997
- Visa applications – from 1997
- Departure and arrival cards – from 19
- 2013 Census
- Births, deaths, marriages, and civil unions – from 1840

Tax / Incom

Income and work data
- Tax and income – from 1999
- NZ Income Survey – from 2006
- Household Labour Force Survey – fr
- Survey of Family, Income, and Employment
- Household Economic Survey – from 2006

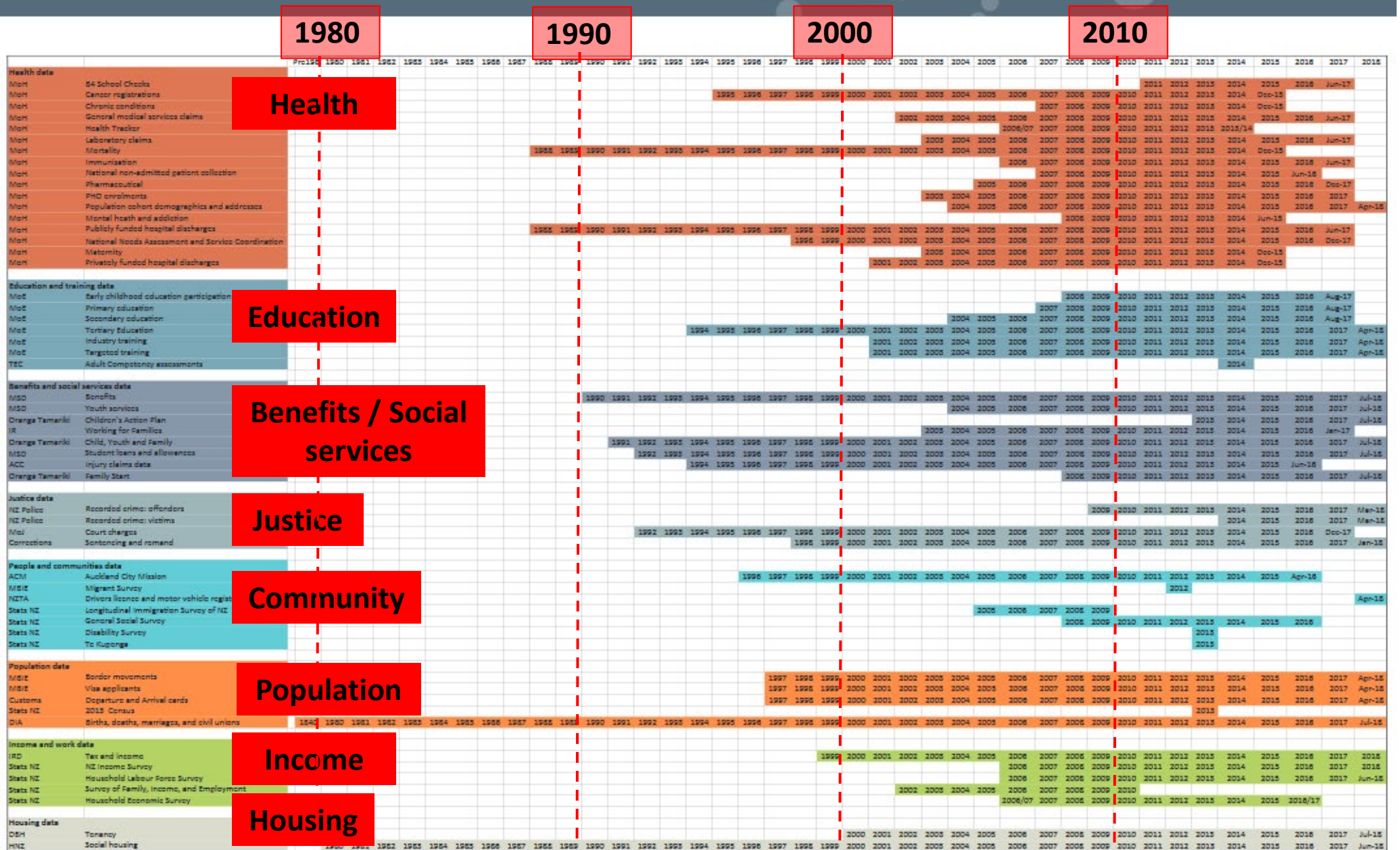
Hous

Housing data
- Tenancy – from 2000
- Social housing – from 1980

60+ data sets and counting

IDI dataset coverage

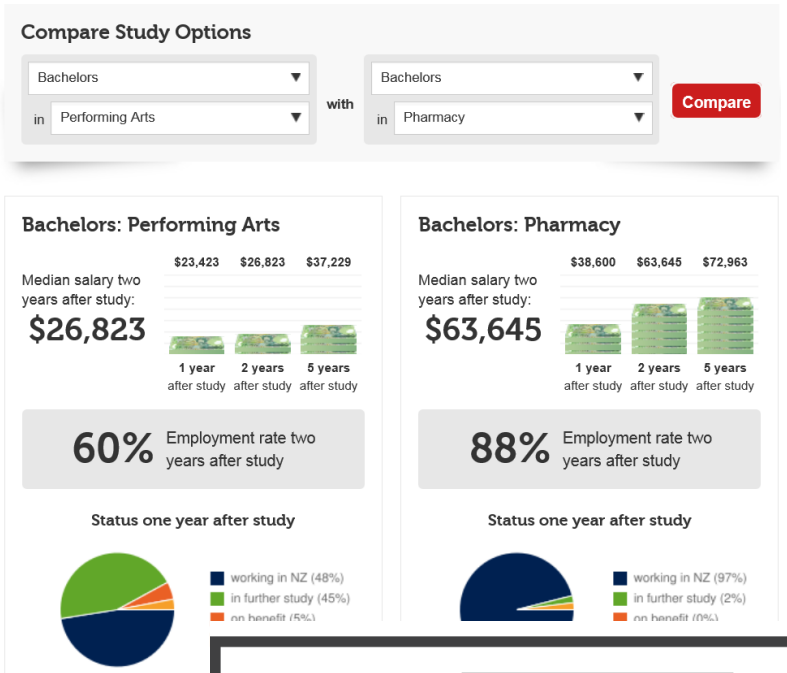
Stats NZ
Tatauranga Aotearoa



Scope is being continuously extended

1840 is earliest. Births, Deaths and Marriages

How the IDI is being used

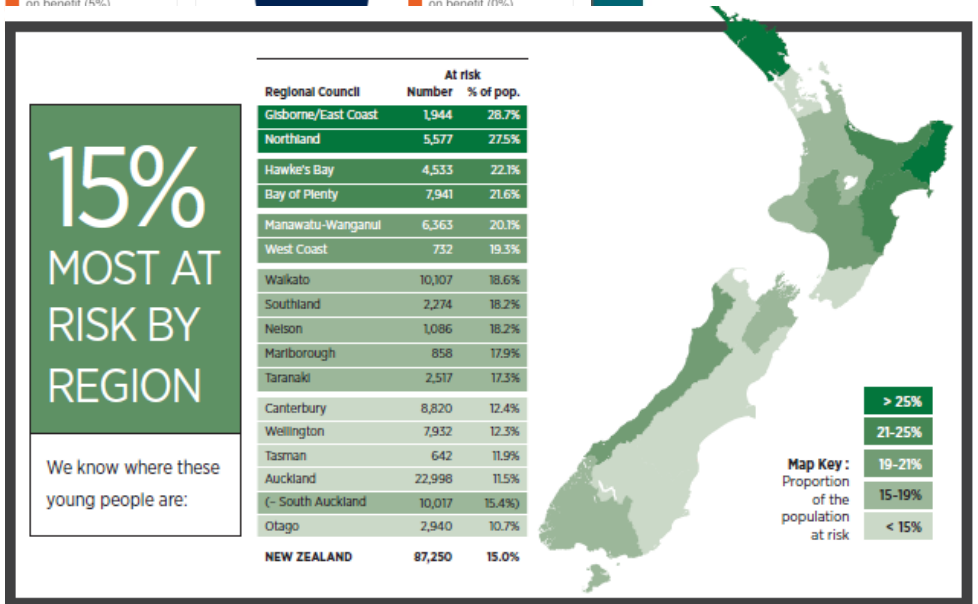


MINISTRY OF BUSINESS, INNOVATION & EMPLOYMENT
HĪKINA WHAKATUTUKI

Temporary Migrants as Vulnerable Workers: A literature review

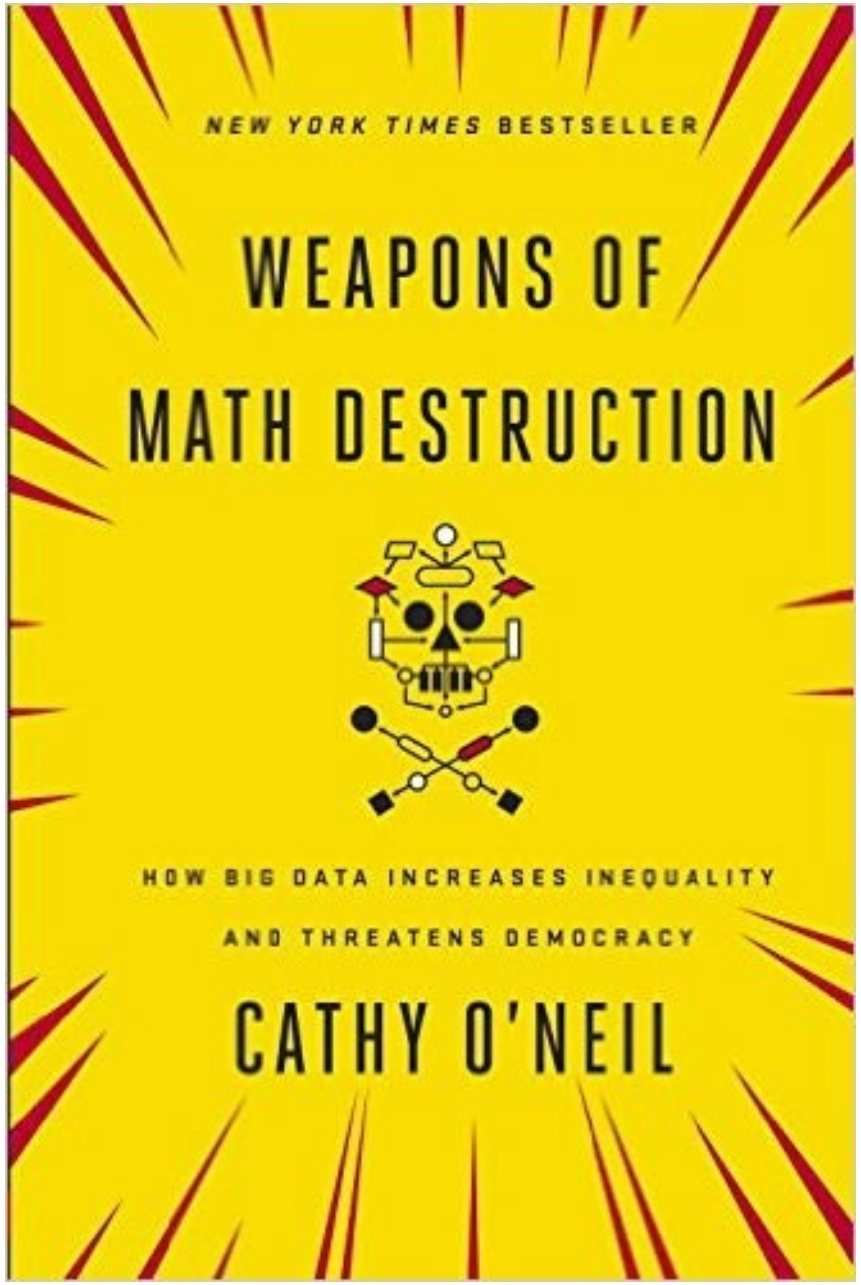
March 2014

Giving children the best start in life...
Family Start



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."

Solution:

- **transparency**
- **engagement**
- **explicability**
- **accessibility**

Elements of due process

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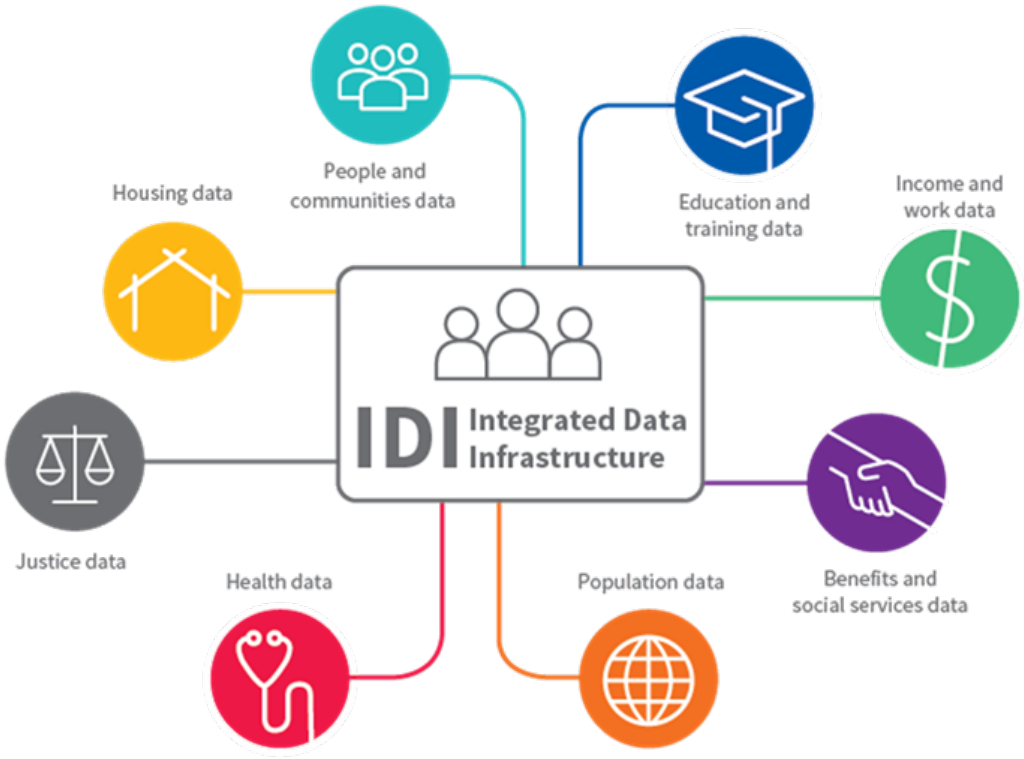
The Problem



Statistical resources are increasingly complex and decreasingly accessible

Awareness of data value

Demand for access to data

High technical barriers to access

Are data relevant to informing local solutions?

Are official statistics for us or about us?

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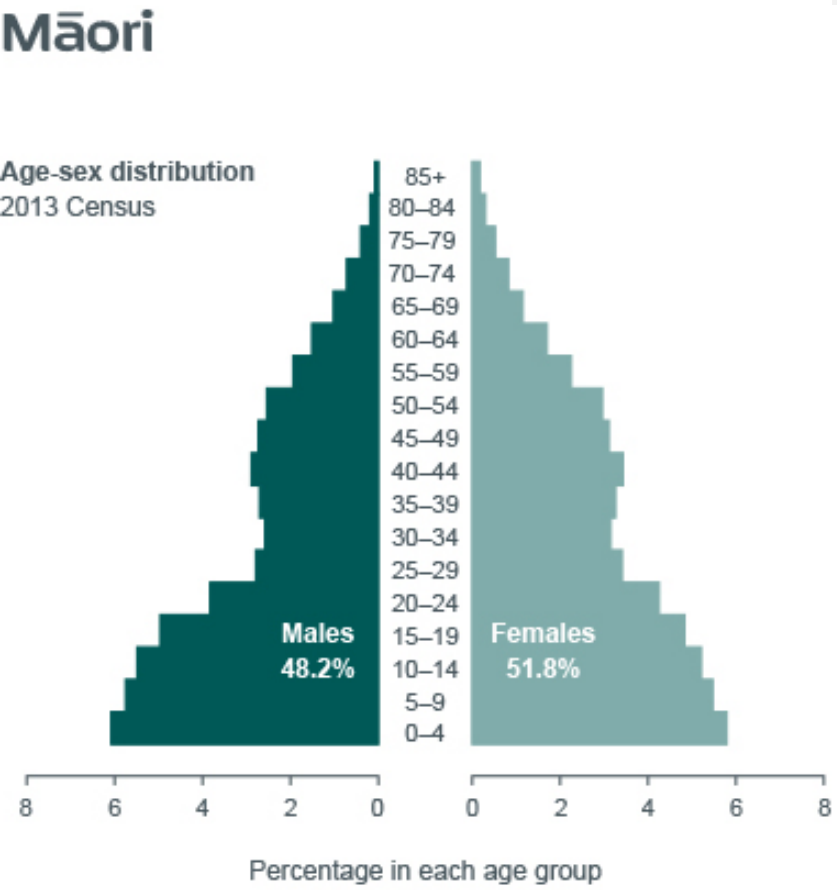
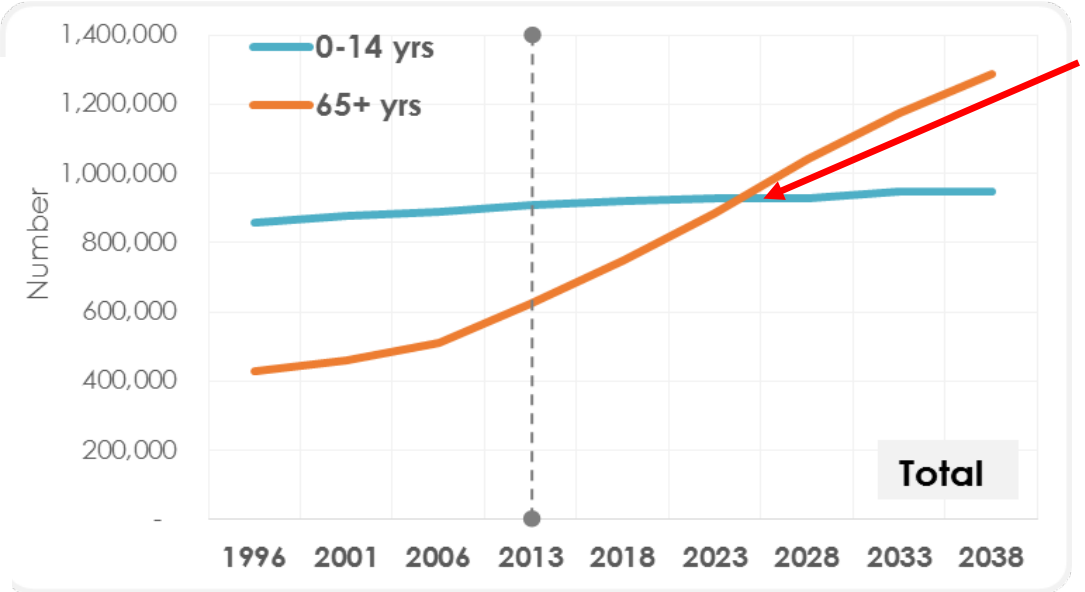
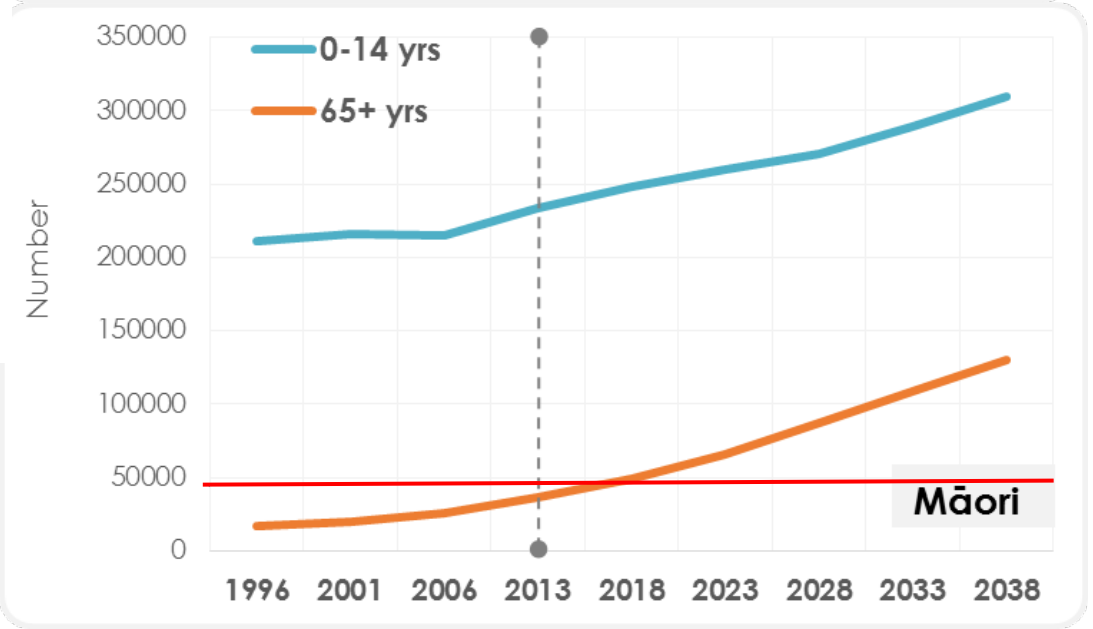
The ‘potential’ demographic dividend





More older people than kids



Prevention will remain a key focus. Ageing population with **social and health** needs

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

SHARE

| 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.

www.mobilitypartnership.org/

DOWNLOAD THIS PAPER

Full Idea Paper

Summary >

Some good data-driven news stories...

Wairarapa Asthma Project
Community intervention.
Very brief duration.
New approach.
Long term reduction in admissions

Focused local effort for national level policies.
Research partnerships
= NEW solutions.

Wahakura
Community intervention.
Just as safe as bassinets.

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Some MORE good data-driven news stories...

CHD1 Gene Discovery and Service Development

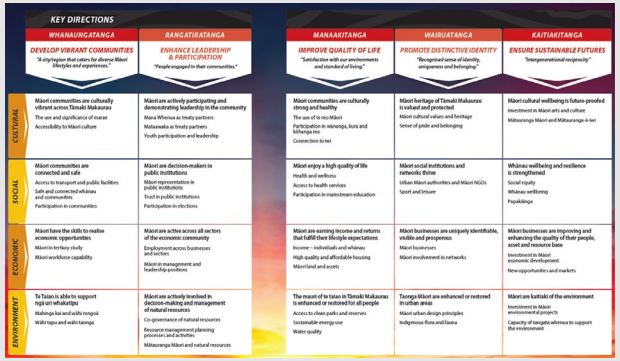
Māori-driven data-informed community development

genomics aotearoa

New variome focused on addressing inequity

Whānau Tahi
NAVIGATING WAYS TO ASPIRATIONAL OUTCOMES

Whānau-orientated data systems



Independent Māori Statutory Board of Auckland Council

National Science Challenges
SCIENCE FOR TECHNOLOGICAL INNOVATION
Kia kotahi mai – Te Ao Pūtaiao me Te Ao Hangarau

Technology to support Māori data and data sovereignty

Culturally Centred Data Sharing and Analytics

Rangi McLeod, Maybelle McLeod, Pauline Harawira

(Ngai Te Rangi)

Hereditary Gastric Cancer Project

- Discovered gene (CDH-1) for Hereditary Diffuse Gastric Cancer
- Now ~500 kindreds worldwide
- Transformed cancer detection, treatment and survival

Combining **two sources of knowledge**
But analytics and protections determined by cultural practices

SC
DEPA

NO STOMACH FOR CANCER®

Government Data Sharing Agreements

nzherald.co.nz

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

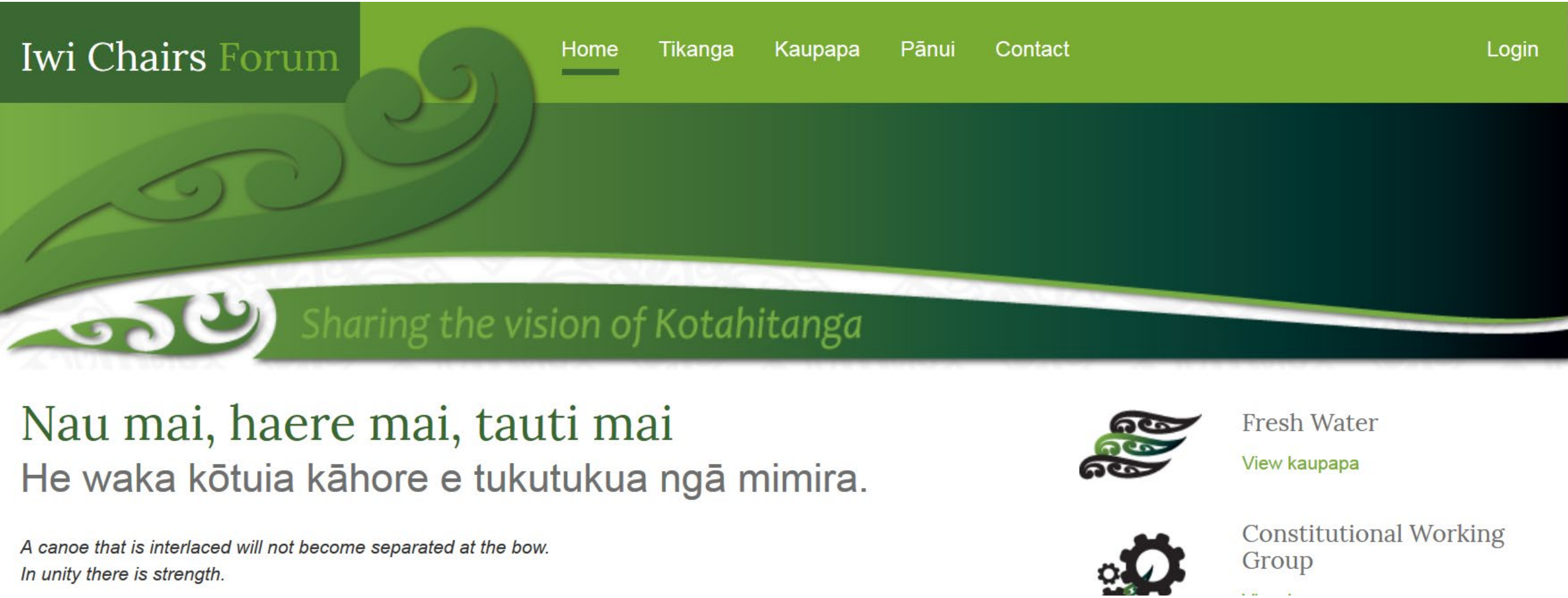
26 Jun, 2018 10:00am
3 minutes to read

Nanaia Mahuta greeting Te Hiku iwi leader Haami Piripi to Wellington
Northland Age

Data access in formal agreements between government and iwi

BUT access needs resources to store and use

Māori Data Governance Structures

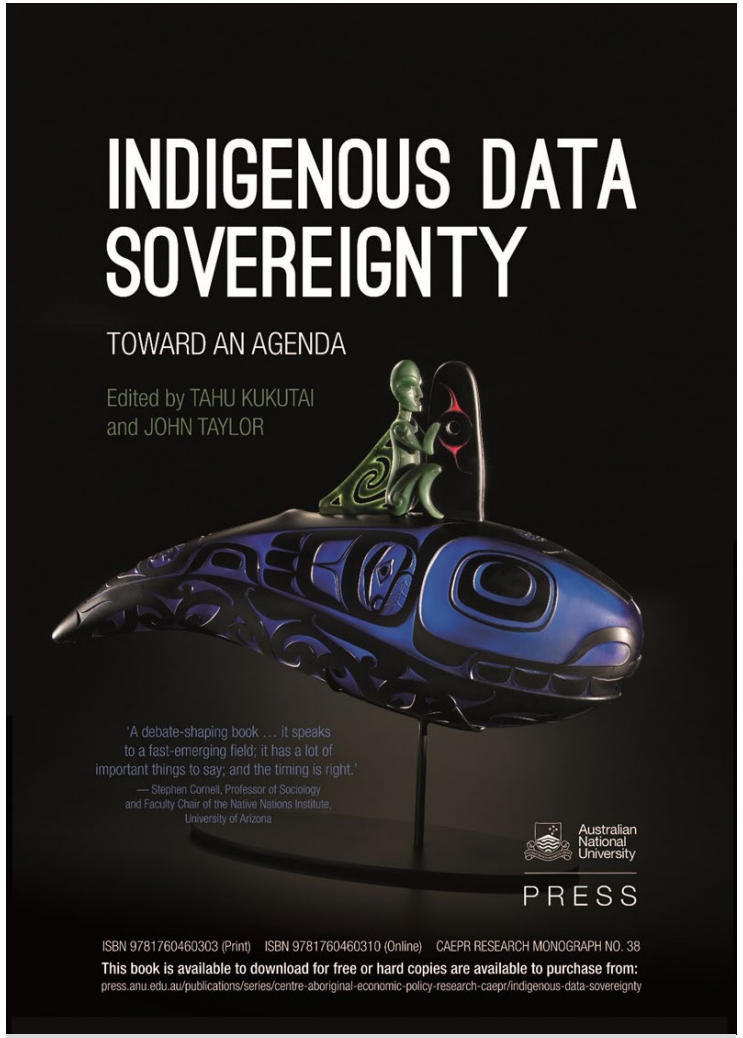


Leading co-governance and co-design discussions with Govt

Indigenous Data Sovereignty

Data Sovereignty states that data is subject to the laws of the nation **within which it is stored**

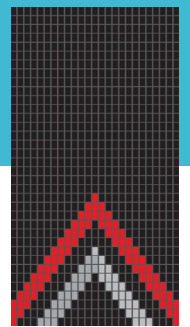
Indigenous Data Sovereignty states that data is subject to the laws of the nation **from which it is collected** (including Tribal nations)

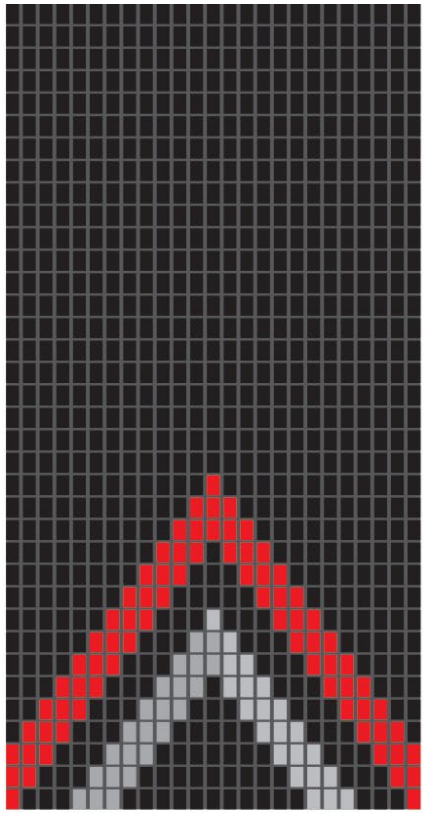


Free to download From ANU press

Māori Data Sovereignty

Is the right of Māori to access, to use, to have governance and control over Māori Data.





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

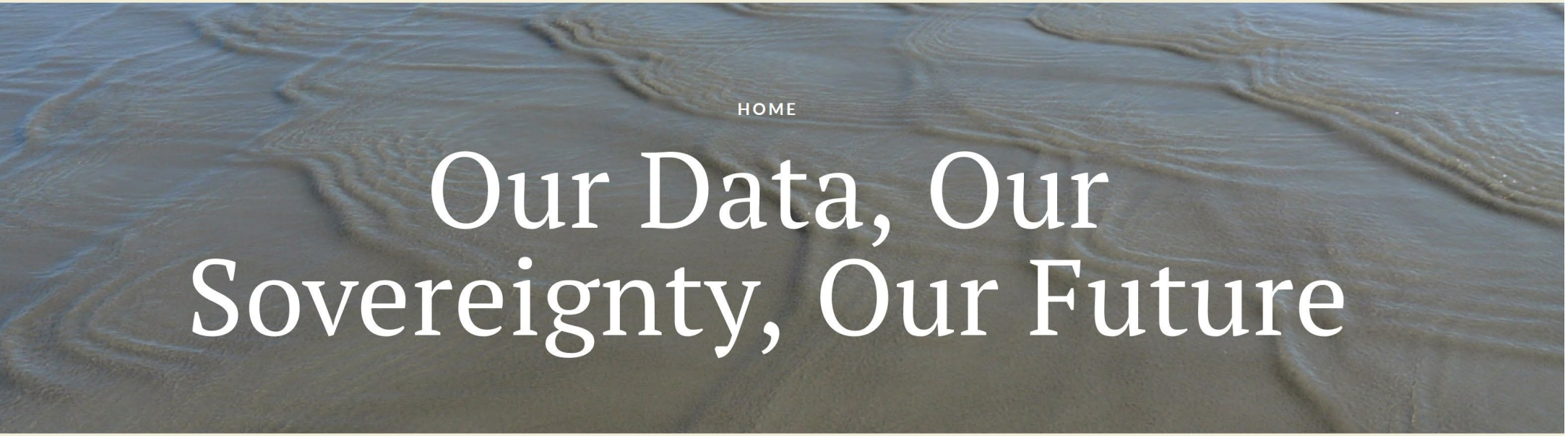
https://www.temanararaunga.maori.nz/

HOME ABOUT US

TE MANA RARAUNGA
Māori Data Sovereignty Network

ACTIVITIES EXPERTS DATABASE JOIN US

MĀORI DATA SOVEREIGNTY NETWORK



HOME

Our Data, Our Sovereignty, Our Future

Nga mihi ki a koutou katoa

Our data, our sovereignty, our future. This vision drove the establishment of Te Mana Raraunga as the Māori Data Sovereignty Network. We advocate for Māori rights and interests in data to be protected as the world moves into an increasingly open data environment.

Contact us

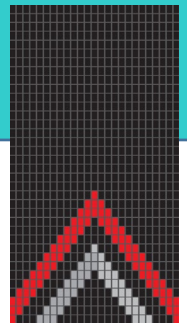
For information or advice

te.mana.raraunga@gmail.com

Resources:
e.g. Māori Data Audit Tools

- **Charter**
- **Principles**

Indigenous Data Sovereignty is supported by International Policy



2007 UN Declaration on the Rights of Indigenous Peoples – Article 15

"Indigenous peoples have the right to the dignity and diversity of their cultures, traditions, histories and aspirations which shall be appropriately reflected in education and public information"

2008 WHO's Commission on the Social Determinants of Health

a 'Minimum Health Equity Surveillance System'. As part of the system, 'good-quality data on the health of Indigenous Peoples should be available, where applicable'.

Research Data Alliance section	Open Data Charter revision	IEEE working group

A COMMITMENT TO INDIGENOUS DATA SOVEREIGNTY (IDS) SPANS THE GLOBE

NATION-STATE BASED, INDIGENOUS LED COMMUNITIES OF PRACTICE

- TE MANA RARAUNGA MĀORI DATA SOVEREIGNTY NETWORK in Aotearoa/New Zealand

TE MANA RARAUNGA
Māori Data Sovereignty Network

- UNITED STATES INDIGENOUS DATA SOVEREIGNTY NETWORK

USIDSN

- MAIAM NAYRI WINGARA ABORIGINAL AND TORRES STRAIT ISLANDER DATA SOVEREIGNTY COLLECTIVE in Australia

Maiam nayri Wingara

- EMERGING NETWORKS:
  FIRST NATIONS, INUIT AND MÉTIS in Canada,
  SAMI/SÁPMI in Sweden

GIDA

THE GLOBAL INDIGENOUS DATA ALLIANCE

Promoting Indigenous Control of Indigenous Data

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gida-global.org

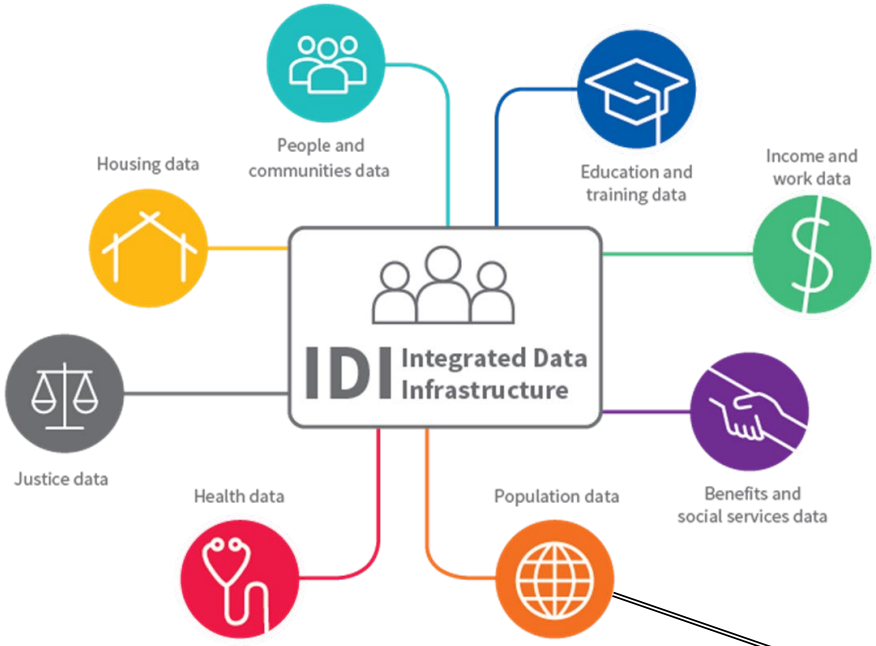
Be
FAIR
Findable
Accessible
Interoperable
Reusable
and
CARE
Collective Benefit
Authority to Control
Responsibility
Ethics

Data Initiatives

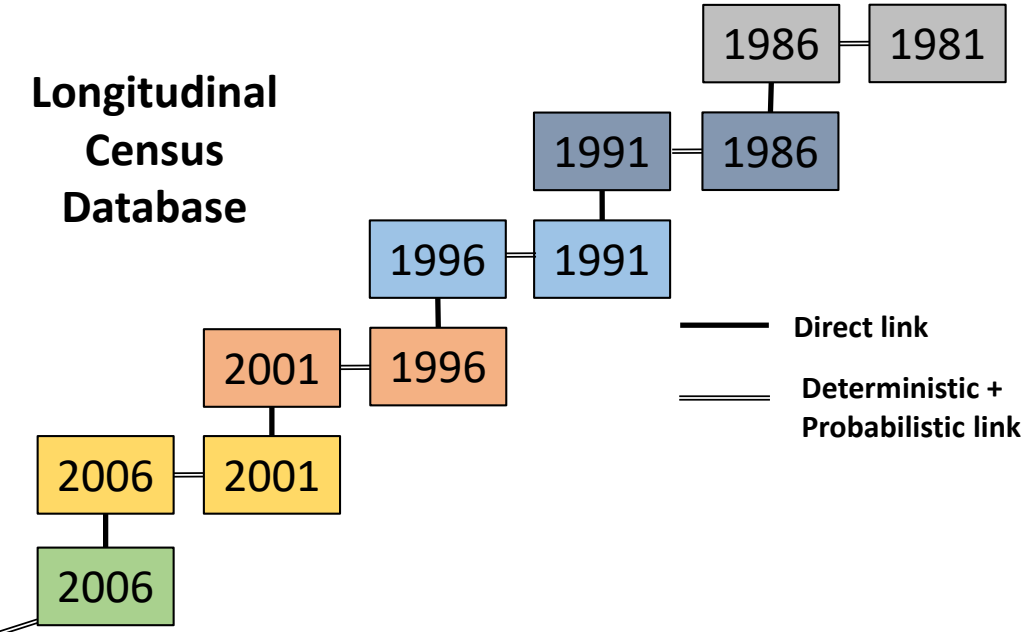
		Source	Status	Scope
DATA USE	Data driven regional development	**Community**	✓	**1 region**
	Local Govt Policy monitoring	**Statute**	✓	**1 region**
GOVERNANCE	Iwi Chairs' Forum Data Group	**Tribes**	✓	**1 region**
	Co-governance of Official Stats	**Govt / Tribes**	**pending**	
RELEVANCE	Tribal data boundaries	**Govt/Research**	✓	**pilot**
	Māori Wellbeing Survey	**Govt**	✓	**National**
	Māori regional capabilities index	**Govt/Research**	**Under development**	**scope**
ACCESS	Māori longitudinal study	**Research**	**Started**	**National**
	Undercount visualiser	**Research**	**Complete**	**National**
	Inequality visualiser	**Research**	**Final Testing**	**International**
	Data Analyser	**Research**	**Complete**	**International**

Data Access

Māori Data and Data Access



Longitudinal Census Database



Source of wellbeing info:

- subjective wellbeing
  - whanau
  - self-reported health status
- social
- cultural
- economic wellbeing

2013 Census — 2018 Census?

Te Kupenga 2013 — **Te Kupenga 2018**

Permanent longitudinal study
+ Tribal
- Geographies
- Identifications

? Data repositories

Identifying GAPS and Informing new data collection

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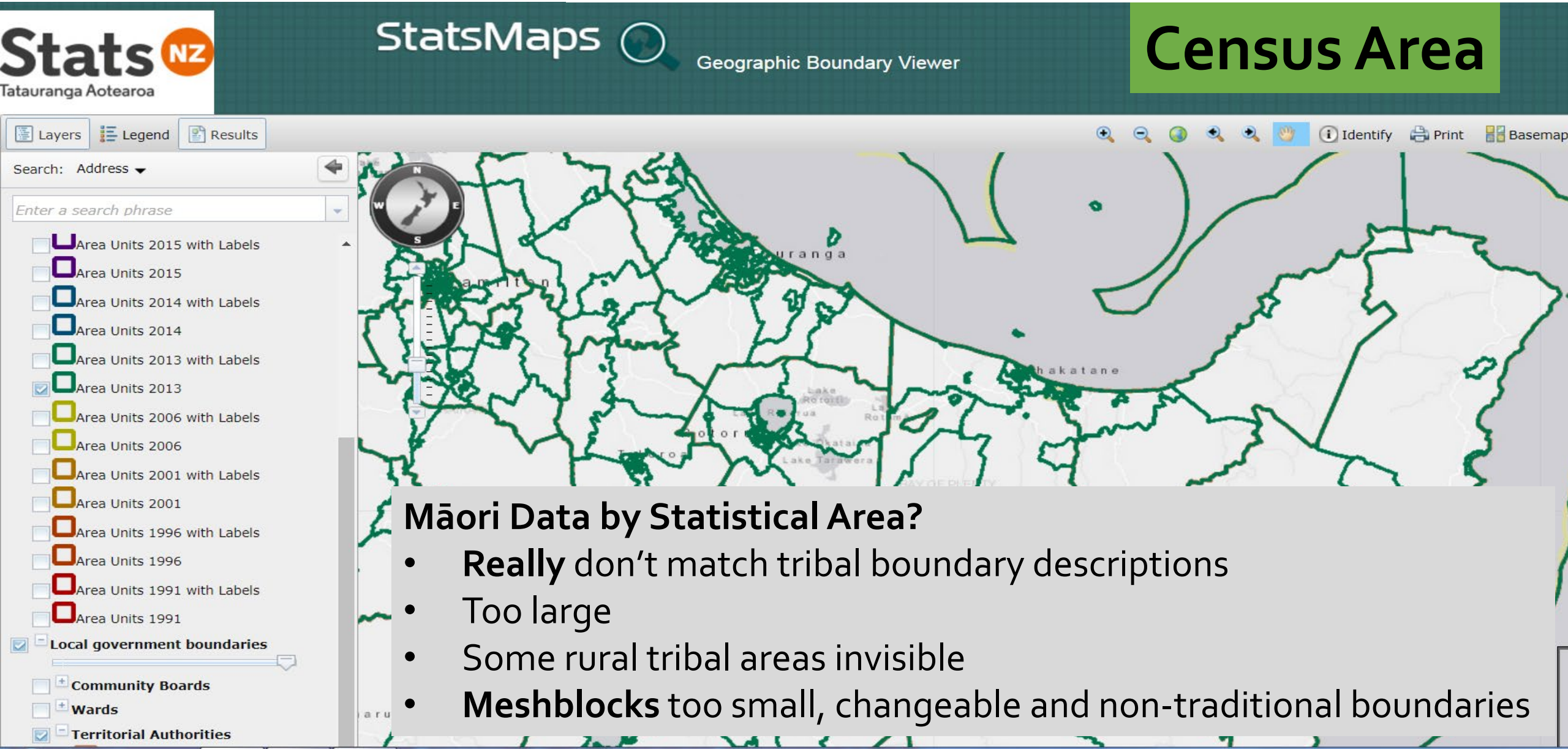
Data Relevance 1

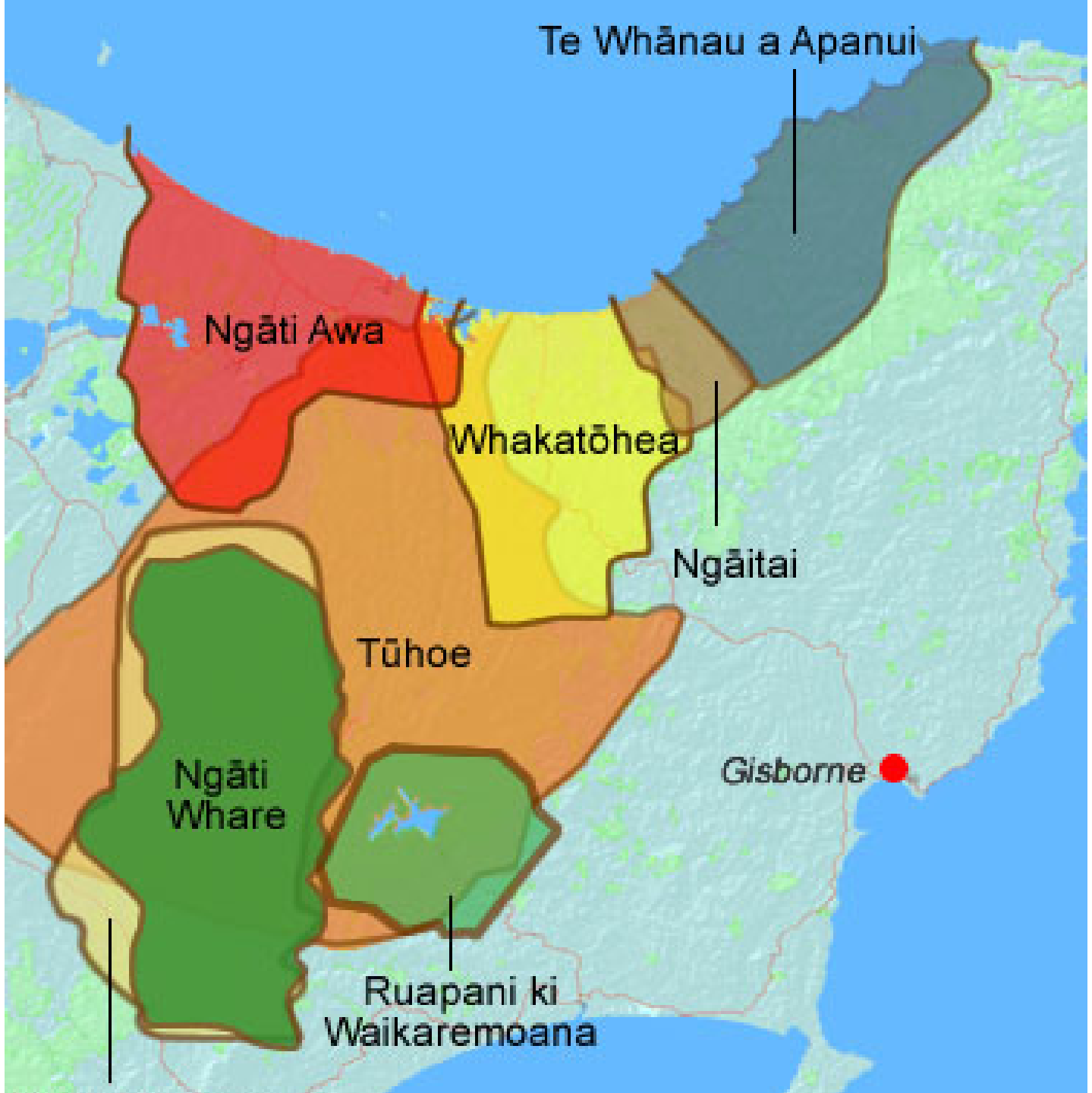
Māori determined data boundaries



Data Relevance 2

A Māori GIS capability to the Official Statistics System

A permanent structural change



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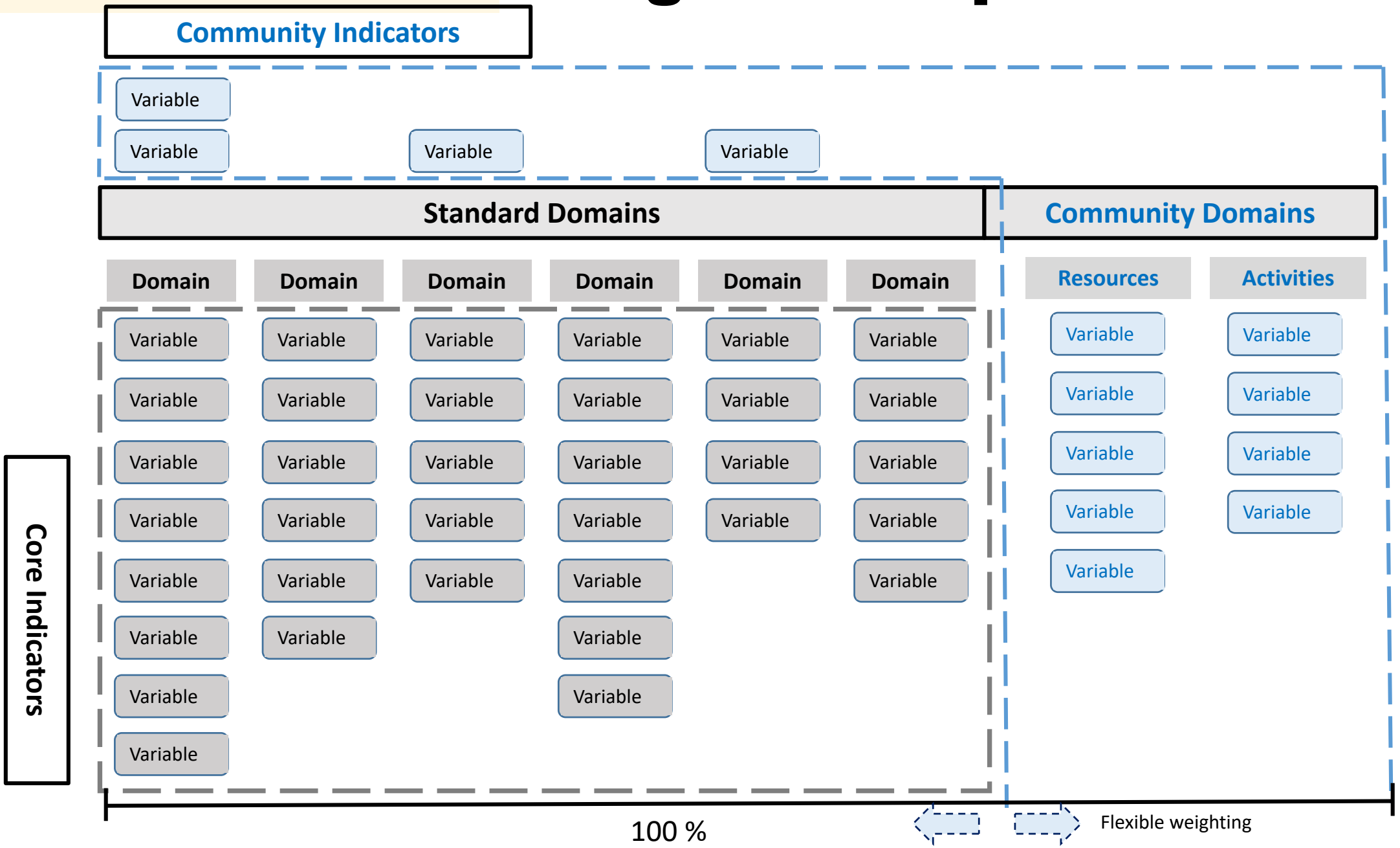
Data Relevance 3

Regional Capabilities Index



Data Relevance 4

The Impact of Indigenous Undercounts

The Impact of Census Undercount on Age-Adjusted Rates

Introduction

This app is designed to show the effect of Census undercount on age-adjusted rates. We use age-adjusted rates as the comparison as they are a commonly reported statistic in official health statistics and are important for assessing the well-being of communities. If the underlying Census data used for these rates is unreliable, this has significant consequences on the ability to use these to help communities.

Start Tutorial

Methodology +

Instructions +

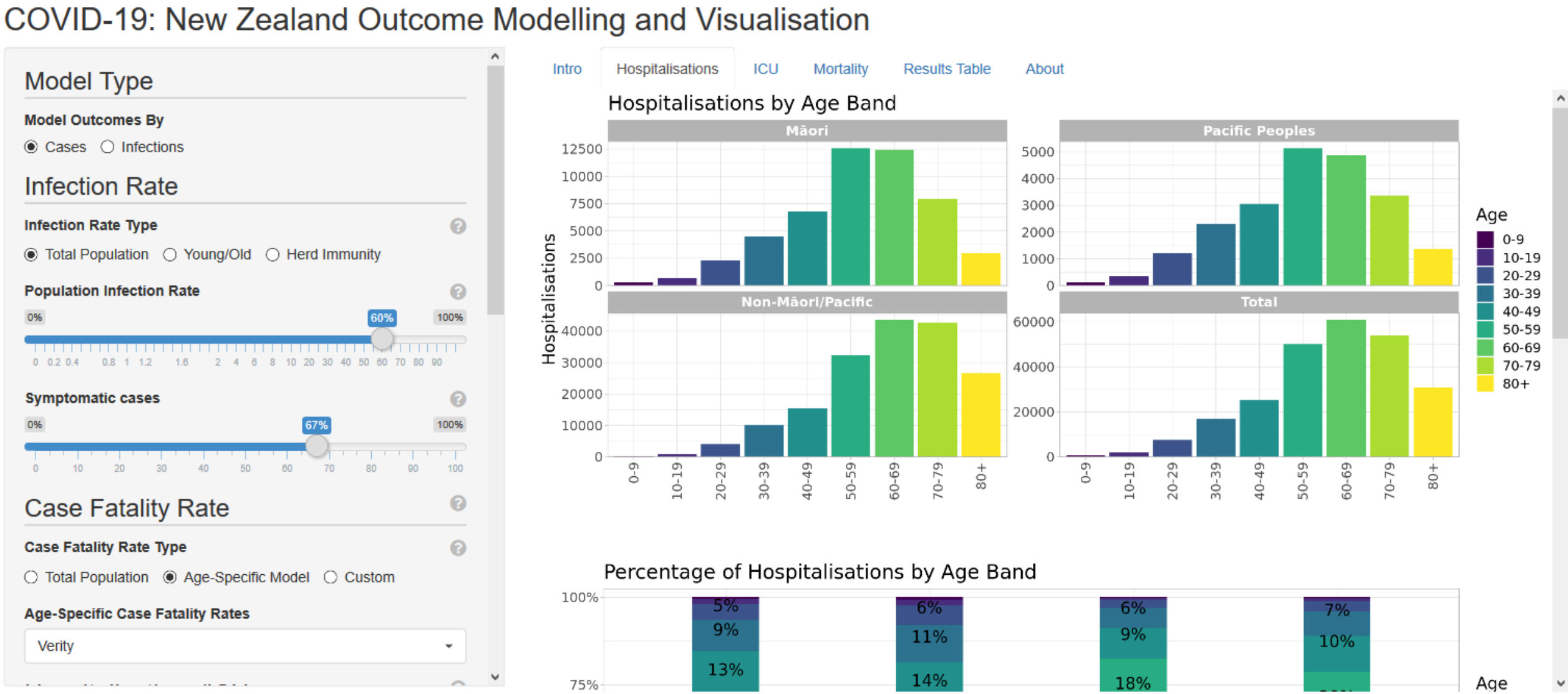
Select Data +

https://daniel-barnett.github.io/census-undercount/

Input Data

Data Relevance 5

Epidemic Inequity at the Regional Level



http://nzcovid19equity.nectar.auckland.ac.nz/covid19-modelling/

Mātau: point and click outcome visualisation

Population Data Visualiser | Summary | Results | Rates | Rate Difference | Rate Ratio | Download | ?

Select an option to increase precision

None

Epidemiology

Using WHO standard population and Keyfitz confidence intervals

Non-Maori Total (Baseline)

Ethnicity: Non-Maori, Sex: Total

Maori Total

Ethnicity: Maori, Sex: Total

Ethnicity

Maori

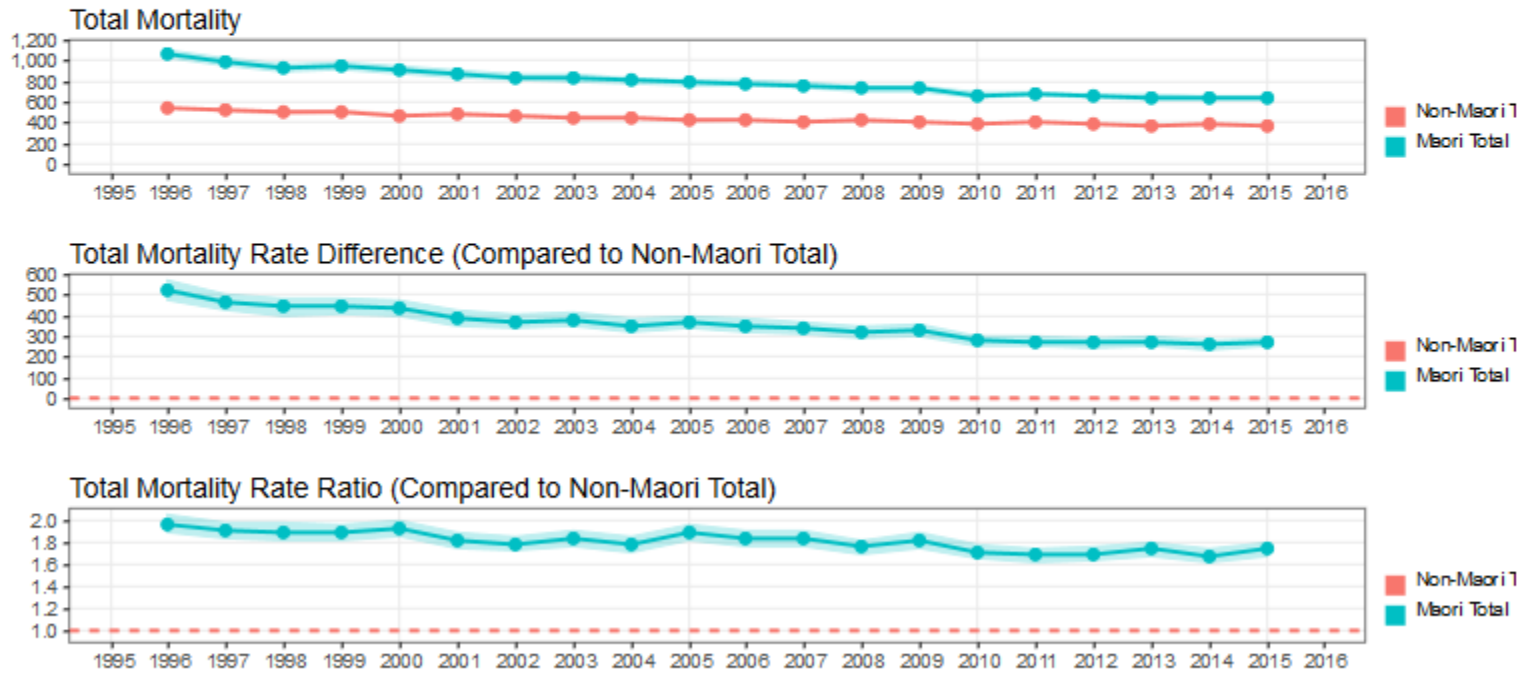
Sex

Total

Total Mortality in New Zealand

Population 1:
Ethnicity: Non-Maori
Sex: Total

Population 2:
Ethnicity: Maori
Sex: Total



Interactive regional maps:

Mātau | SUMMARY | RESULTS | RATES | RATE DIFFERENCE | RATE RATIO | DOWNLOAD | ?

Non-Māori Total (Baseline)

Ethnicity: Non-Māori, Sex: Total

Ethnicity: Non-Māori

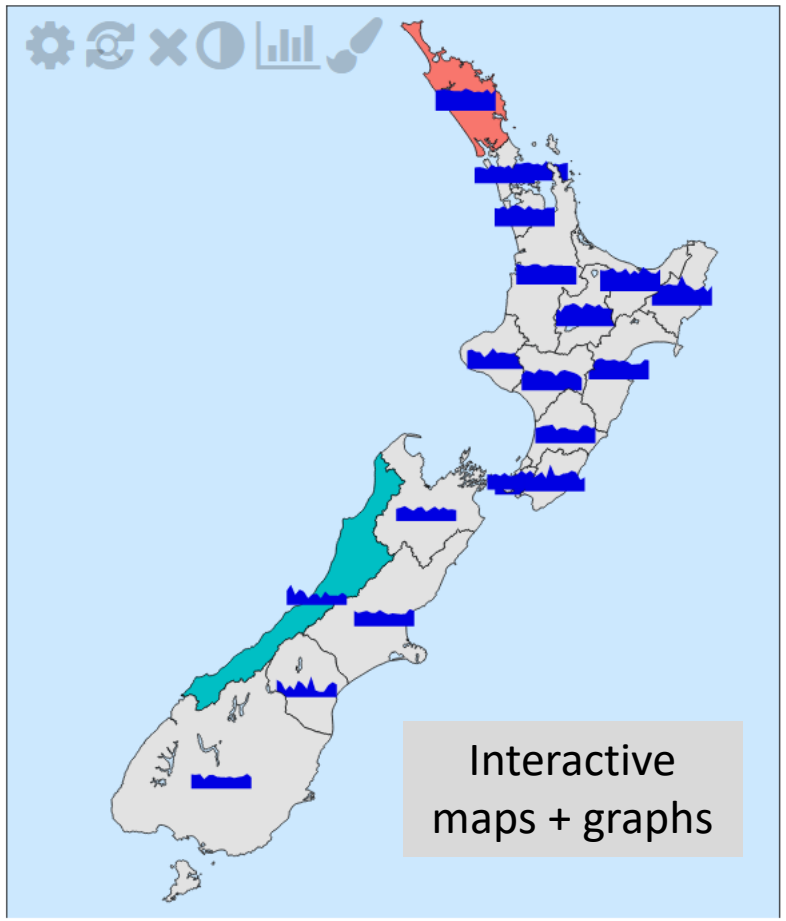
Sex: Total

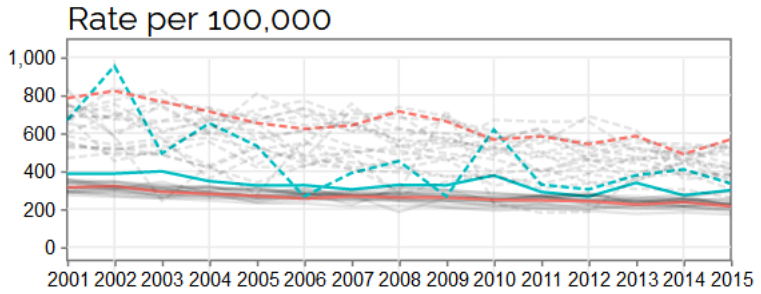
Māori Total

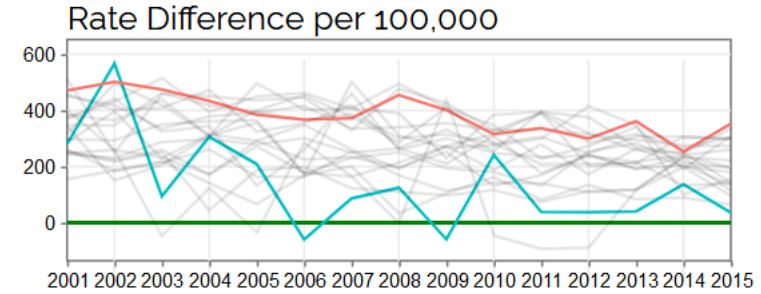
Ethnicity: Māori, Sex: Total

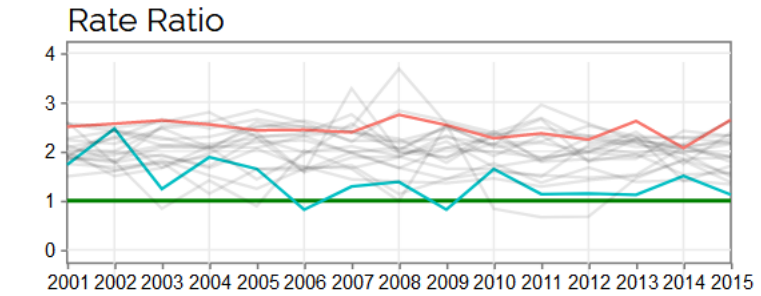
Ethnicity: Māori

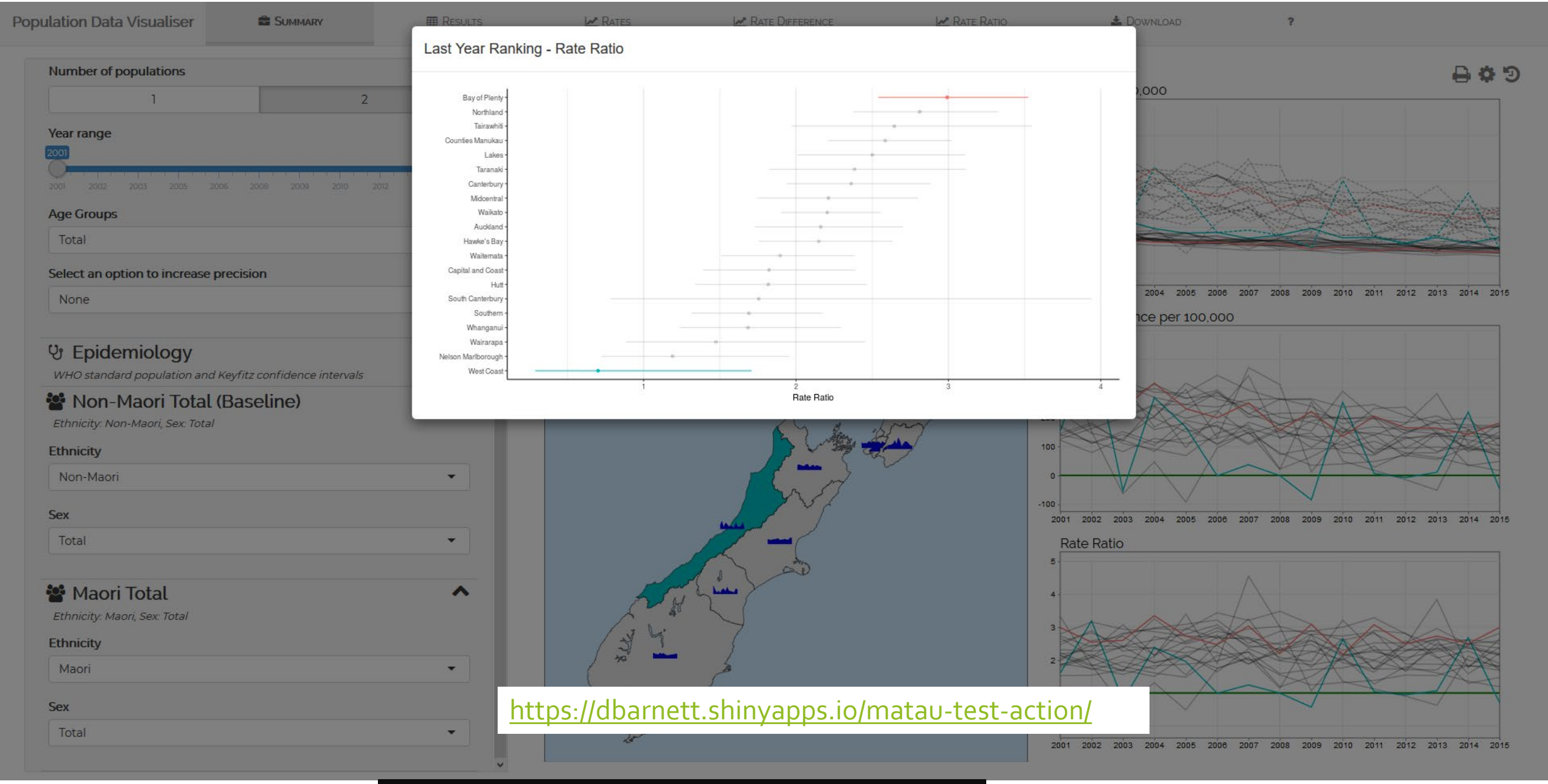
Sex: Total










Population Data Visualiser
Summary
Results
Rates
Rate Difference
Rate Ratio
Download
Number of populations
1
2
Year range
2001
Age Groups
Total
Select an option to increase precision
None
Epidemiology
WHO standard population and Keyfitz confidence intervals
Non-Maori Total (Baseline)
Ethnicity: Non-Maori, Sex: Total
Ethnicity
Non-Maori
Sex
Total
Maori Total
Ethnicity: Maori, Sex: Total
Ethnicity
Maori
Sex
Total
Last Year Ranking - Rate Ratio
Bay of Plenty
Northland
Tairawhiti
Counties Manukau
Lakes
Taranaki
Canterbury
Midcentral
Waikato
Auckland
Hawke's Bay
Waitemata
Capital and Coast
Hutt
South Canterbury
Southern
Whanganui
Wairarapa
Nelson Marlborough
West Coast
Rate Ratio
Rate Ratio
https://dbarnett.shinyapps.io/matau-test-action/
https://dbarnett.shinyapps.io/popvis2/

Emerging solutions in NZ

Data Use	Data Governance	Data Relevance	Data Access
Regional data informed development	Iwi Chairs Forum Data Leadership	Indigenous boundaries	New studies
Local Govt policy monitoring	Co-Governance Discussions	Supplementary variables	New Data Tools
		Regional Capabilities Index	

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How do we get there?

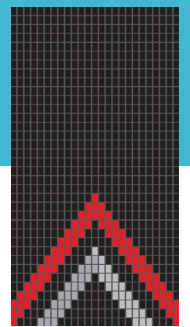
Information: access and governance

Translators: capability to use

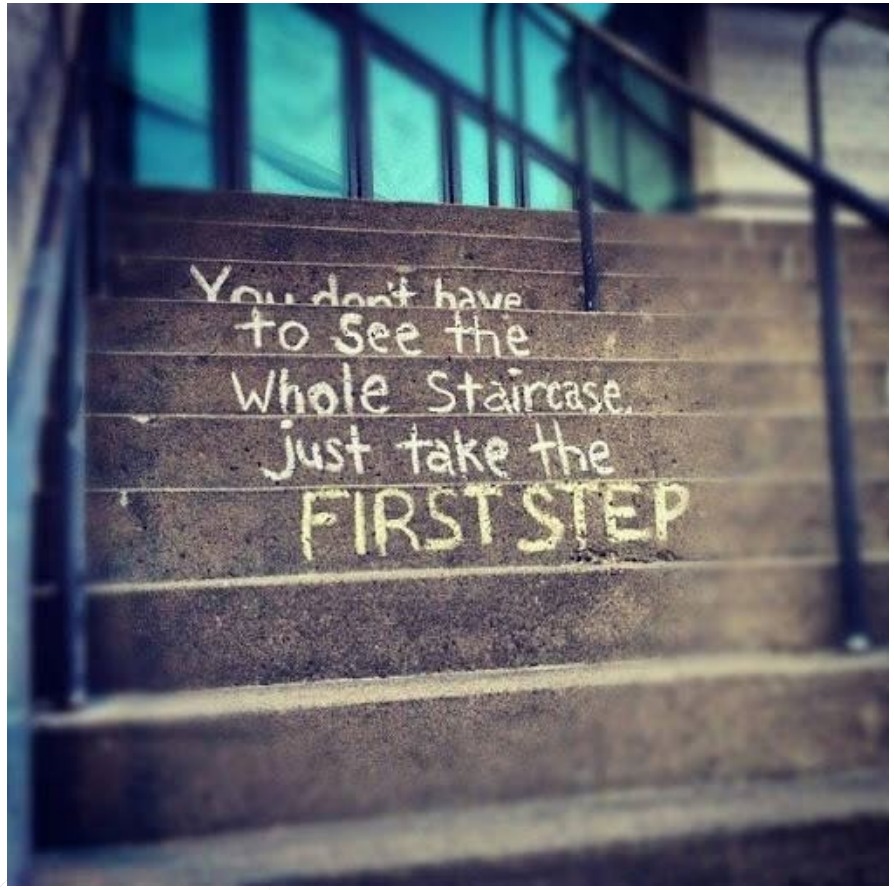
Infrastructure: control and design the future

*"Whāia te **ITI** kahurangi, ki te tūohu koe, me he maunga teitei"*

Seek the treasure you value most dearly; if you bow you head, let it be to a lofty mountain



Re-orientating the Data System to inform Advancement



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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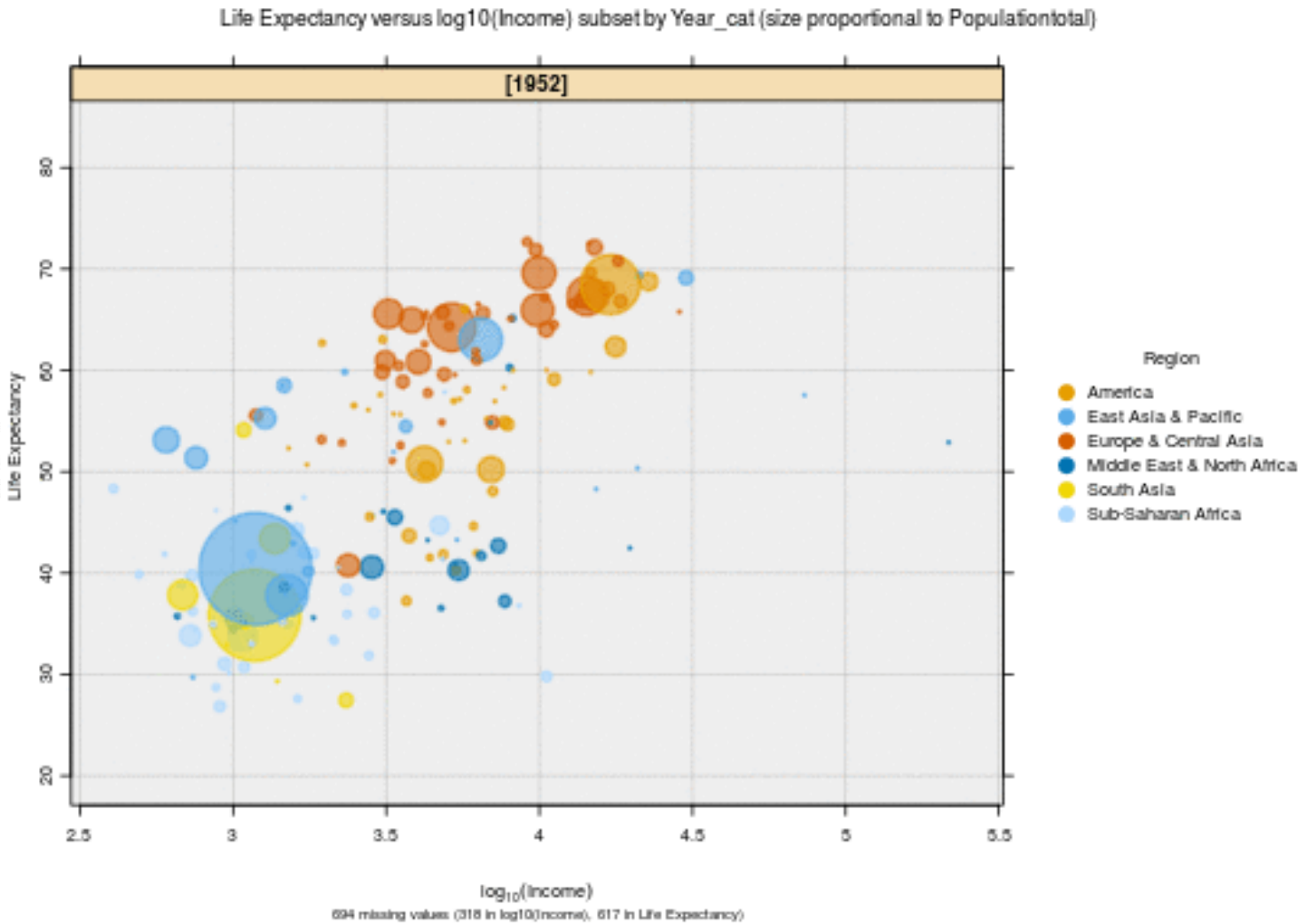

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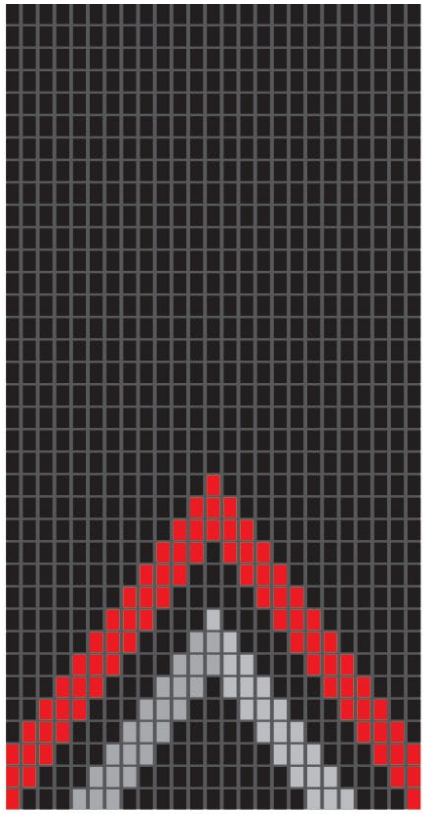


TE MANA RARAUNGA

Māori Data Sovereignty Network

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

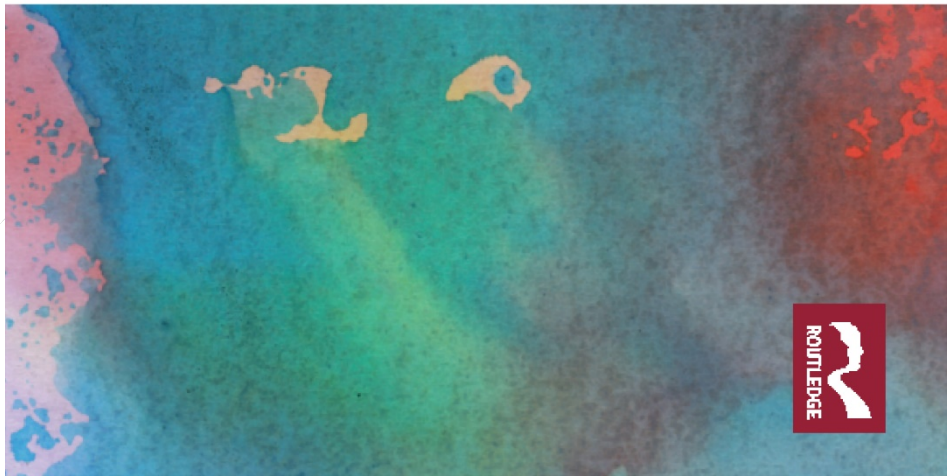
- Data rights and interests
- Data governance
- Data storage and security
- Data access and control

Data is a valuable strategic resource

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

INDIGENOUS DATA SOVEREIGNTY AND POLICY

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



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By Maggie Walter, Tahu Kukutai, Stephanie Russo Carroll, Desi Rodriguez-Lonebear

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