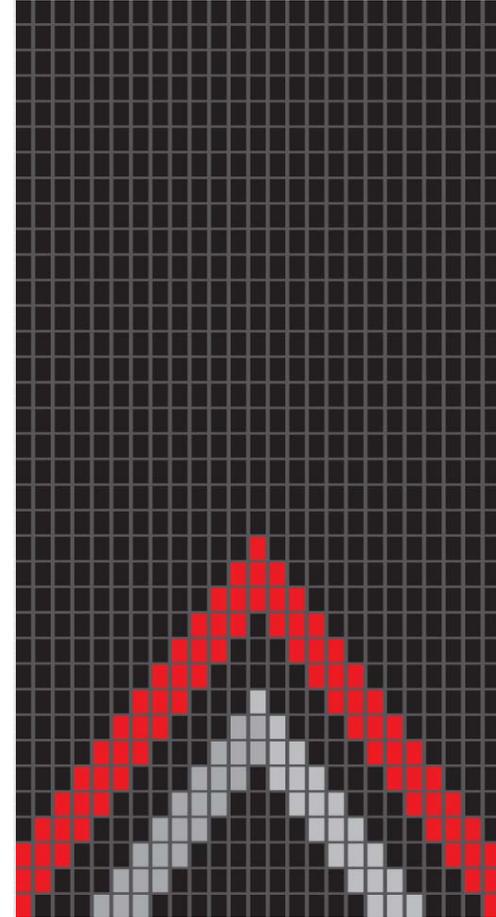


Data, Development and Sovereignty

Big Health Data Workshop -
January 2016

Andrew Sporle - on behalf of Te Mana Raraunga



Presented at:

Big Health Data for Epidemiology: opportunities and challenges using the SNZ IDI and other sources of "big data" for epidemiological research in NZ. University of Otago, Wellington, 26 January 2016.

**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'.

**Indigenous
Data
Sovereignty is
already
happening
internationally**

**International Group
for Indigenous
Health
Measurement
- since 2005**

United Nations

- Dept of Economic and Social Affairs
- Special Rapporteur on the rights of Indigenous peoples
- Permanent Forum on Indigenous Issues

**ASSA
International
Workshop
Canberra 2015**

**Native American and
Indigenous Studies
Association 2016 conf**

Cree Nation - OCAP[©]

- Ownership
- Control
- Access
- Possession

**Meanwhile, in
Aotearoa
Data
Sovereignty is
already a
significant
issue**

**Iwi wanting access
to and possession of
data for their own
development (OIA,
Treaty claims and
now IDI)**

**Regional health data
sharing agreement
includes data
sovereignty**

**Treasury /
SNZ hui**

**Iwi chairs
forum hui**



**Te Mana
Raraunga**

**Independent
Maori
Statutory
Board appoint
Data Strategy
Expert Panel**

Data is a highly valuable strategic asset for Maori development

In the age of Big-Data, Maori want

- **access to data** to support our decision-making
- **to be involved** when big-data is used to **make decisions** about us
- **Indigenous Data Sovereignty** states that data is subject to the laws of the nation from which it is collected (incl Tribal nations)
- **Maori Data Sovereignty** recognizes that Maori data should be subject to Maori governance.
- Maori Data Sovereignty supports **iwi sovereignty** and the realisation of iwi aspirations.

What is Māori Data? (depends who you ask but)

Context and kaupapa is important

Data from Māori

- From Maori organisations and businesses
- Cultural or commercial significance

Data about Māori

- Used to describe or compare Māori collectives
- Cultural or commercial relevance
- Individuals?

Data about Māori resources

- Emerges from research on Maori resources
- Cultural or commercial interest

Issues with Linked Health Data for Maori

Require
ancestry
and iwi
information

Availability
of Hauora
measures

Deficit or
development
measures /
approaches

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

The Potential
of Linked
Data to
inform Maori
development
is recognised

Maori providers and researchers moving rapidly into this space – but...

To what extent can **Maori engage** with and **benefit** from the linked data resources?

- Technological and skill barriers to engagement
- Measures and approaches must match Maori aspirations
- social licence/consent/partnership/ or control

A **Top-down approach** to driving these initiatives does not match up well to Maori development parameters or models of engaged partnership

So, what do we do?

Build Capability

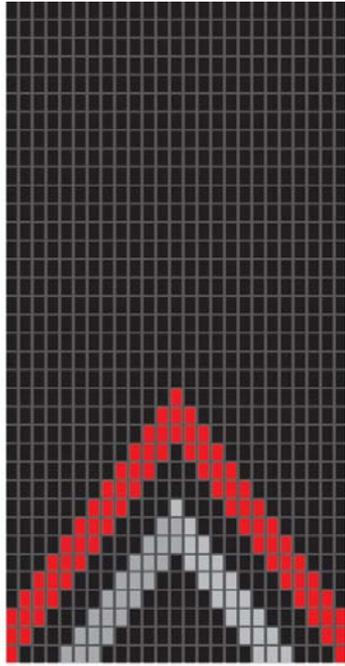
- Include Maori definitions
- Address data quality
- Include development measures
- Ensure Sustainability (?Census)

Build Capacity

- Awareness of the IDI system
- Improve accessibility
- Pilot projects
- Workforce development

Engagement

- Ensure participation
- Address governance
- Resolve ownership



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