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

CoMPASS Symposium. Tāmaki Campus. June 2018.



SCIENCE DEPARTMENT OF STATISTICS **Andrew Sporle**

Māori Development Goals

(Durie MH 2003)



'Potential' demographic dividend in a Post-Settlement Context





Data is a social product – and so is analysis

Imperfect data, imperfect models, embedded values can create selffulfilling feedback loops.

SCIENCE





"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



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



SCIENCE DEPARTMENT OF STATISTICS 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/nM RR = 1.6

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



ΝΕΨ ΖΕΔΙΔΝΓ

Standardised to Māori population

Source: DoH and MoH Mortality collection data via Data Visualiser

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Identifying intervention points

Data and Inequitable Impact

Ministry of Health Amenable Mortality Relative Risk





THE UNIVERSITY OF AUCKLAND Te Whare Wanaga o Tamaki Makaurau NEW ZEALAND

Standardised to WHO population

Source: DoH and MoH Mortality collection data via Data Visualiser

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Data and Identifying Inequitable Processes?



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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



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

Kirikowhai Mikaere

(Data is the new land)

TE MANA RARAUNGA

Māori Data Sovereignty Network

Data is a valuable strategic resource

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

Māori Development Parameters (some)



Data Initiatives and Māori Development

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



TRANSFORMATION

THE SOLUTIONS

Māori driven community development





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 whanau 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

System

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Data Visualisation

Workforce development

Māori data capability

Data system responsiveness

Creating triballydefined geographic boundaries for **Official Data**



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





Geographic Boundary Viewer



StatsMaps 🔘

Geographic Boundary Viewer

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(i) Identify

Meshblocks

Possibly re-sort existing meshblocks?

But meshblocks:

- don't match tribal boundary descriptions
- lack detail
- change over time
- small size = large error from confidentialisation process

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





Changing the Map: Making data local



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.



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

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



Te Hao Nui - Māori longitudinal capacity in the OSS



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Re-orientating the Data System to inform Development





| SCIENCE |
|--------------------------|
| DEPARTMENT OF STATISTICS |

Combined commitment to change

Universal Outcomes: Māori Specific Data system monitoring **Outcomes:** of local and national Supporting locally driven inequity innovation to match need Changing Māori data capability What is measured Workforce Who can access it How it is accessed Technology How it is analysed



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

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