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

CoMPASS Symposium.
Tāmaki Campus. June 2018.
Māori Development Goals

(Durie MH 2003)

Best Outcomes for Māori

Universal Outcomes

+ Māori Specific Outcomes

GOALS

- Human Potential and Whānau Development
- Strengthen Māori Society
- Wealth Creation and Knowledge Economy
- Development of Māori knowledge, language and culture

Almost ALL data on this bit

Individuals

Whānau, Hapū, Iwi

Nation
‘Potential’ demographic dividend in a Post-Settlement Context

More older people than kids

Opportunity for major impact of lifecourse and inter-generational research
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

Māori/Non-Māori relative risk for amenable mortality 1996-2013
Standardised to Māori population
Source: DoH and MoH Mortality collection data via Data Visualiser

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

Ambulatory sensitive hospitalisation rate
M/nM RR = 1.6

Identifying intervention points
Data and Inequitable Impact

Standardised to WHO population
Source: DoH and MoH Mortality collection data via Data Visualiser

Amenable Mortality (MoH)

Regional variation in service impact for Māori

Identifying intervention location
Inequalities in colon cancer survival between Māori and non-Māori arise due to lots of small differences cumulating.

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

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
- 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 Rodriguez-Lonebear
“He whenua hou, 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
- Co-design
- Co-collection
- Maintaining Social and Cultural licence
- Māori capacity building

- Protecting Māori interests
- Transparent methods
- Individual and Collective measures
- Ownership and use resolved
- Māori determined content
- Māori methodology

- Social and Cultural licence
- Māori capacity building
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**Risks**
- Māori development dividend
- Data system backlash

“It’s not for us, it’s about us”
Māori driven community development
RARANGAHIA TE TAURAWHIRI TÂNGATA KIA HUA AI TE MÂRAMA
BRINGING PEOPLE TOGETHER TO MAKE A DIFFERENCE

Our foundation
Sharing knowledge and information
Working together to progress stronger communities

OUR MAUNGA
Toto te Maunga

OUR PEOPLE
Toto te tangata

OUR STORIES
Toto te kupu e

Focus areas >

EDUCATION
- Increase Numeracy & Literacy attainment
- Increase school leavers attaining NCEA Level 2 or above

Opportunities >

1. Ruapehu Learning Journal
2. Whanau Reading, Literacy & Numeracy Programme
3. Community Tagging
4. NCEA & Whanau events

Solutions >

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 Analyses
9. 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
14. Research alternative housing developments

HEALTH
- Increase availability & access to health services
- Collaborate across service providers

15. Haurora Navigator
16. Wellbeing Expo
17. Haurora Yellow Pages
18. Integrated Service Centre – a one stop shop
19. Ruapehu ToddTown
20. Extend Kaikō Whanau programme
21. Community Values (Makung, Tangata, Tukotahi)
22. Community technology hub
23. Street by street initiative

Our Purpose >

To enable whanau transformation in the Ruapehu rohe
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

Official Statistics System

- Māori GIS project
- Iwi Statistical Standard Review
- Local Māori Data Needs
- Māori longitudinal capability within the OSS
- Data Visualisation
- Workforce development

Data system responsiveness

Māori data capability
Creating tribally-defined 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
So maybe Census Area Unit?
• Really don’t match tribal boundary descriptions
• Too large
• Some rural tribal areas invisible
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

Tribal Governance

Generation and Collection of own Data

Protocols
Map (s)

Access
Data

Statistics NZ
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.

Māori well-being

- Social
- Economic
- Cultural

Cultural

- Spirituality (Wairua)
- Cultural (Tikanga)
- Language (Te reo Māori)
- Relationships (Whanaungatanga)

Whānau and Whānau Well-being
Source of wellbeing info:
- subjective wellbeing
  - whanau
  - self-reported health status
- social
- cultural
- economic wellbeing
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
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/