

# Health Information: moving from wrongs to rights

Health Informatics New Zealand  
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## Information - From Wrongs to Rights

Fascination aside

Ethical standards agreed upon

The most important question remains –

- **Information - for what purpose?**

- superficial
- societal

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Journey's end or

Journeying safely

- challenging issues at destination end  
including equity

Health informatics as a tool of navigation

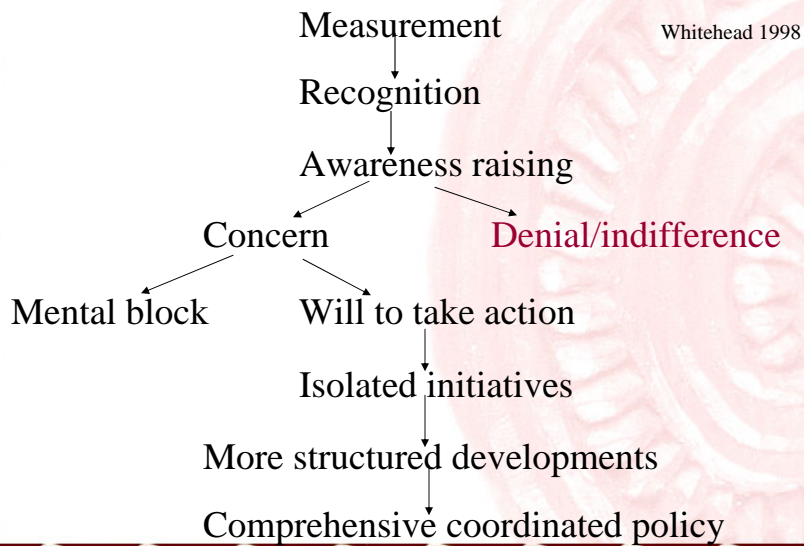
a tool to be constantly contextualised at  
a higher level of purpose

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**EQUITY**

**- eliminating ethnic inequalities**

## Action Spectrum on Inequalities



## Discourses of Denial

1. We need more evidence
2. Genetic inferiority
3. Deservedness as access criteria to health
4. Individual responsibility for your health behaviours
5. Interventions are racist

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- Denial of inequalities
  - discourses of wrongs
- Inequalities, disparities and gaps
  - discourses of needs
- Inequities
  - discourses of rights

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### The Trouble with Health Science

- theoretical position in positivism
- the truth exists,
- it's out there and we must find it

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### Life in a Post-modern World

- there are many truths
- many views from different mountaintops

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### Information Myths

- data speaks for itself

% school leavers with formal qualifications	
No	16 : 39
Yes	84 : 61
	nM : M

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Information Myths

- data speaks for itself
- gaze – “the focus of inquiry”
  - example - melanoma and parity

## Theory Frames Interventions

Another headline example:

500 teenage girls got pregnant last year

Naming, shaming and blaming

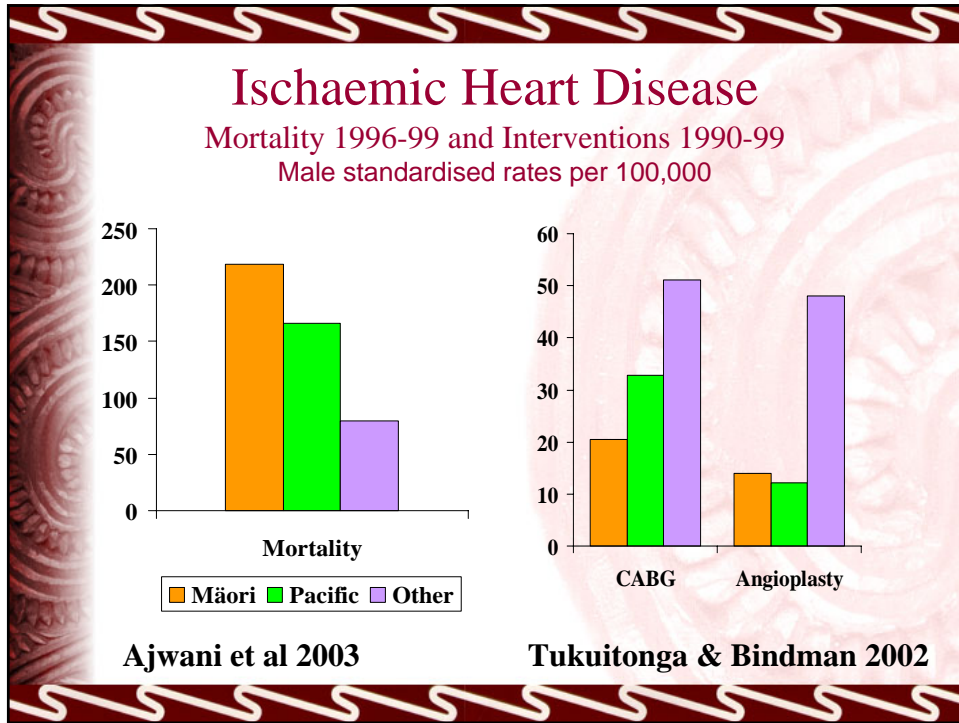
Gaze at the “problem”

Privilege is silent

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Information Myths

- data speaks for itself
- gaze – “the focus of inquiry”
  - example - melanoma and parity
  - Maori problem or pakeha privilege



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Information Myths

- data speaks for itself
- gaze – “the focus of inquiry”
- *the* Maori perspective

## bell hooks

- avoid romanticism
- reject binary debate – all good – all bad
- our right to complexity

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### Indigenous Rights

- UN Draft Declaration on the Rights of Indigenous Peoples
- “ the right of indigenous peoples to self determination”

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### Indigenous Rights

- includes the collective and individual right to identify ourselves as indigenous and to be recognised as such

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### Indigenous Rights

- also includes the right of access to public goods and services, and
- the right not to be subjected to propaganda, and
- the right to freedom from discrimination

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### About Identity

- an identity spectrum from individual characteristics through family, tribal regional and ethnic identities to national and global.
- all valid expressions dependant on situation
- pressure to limit these definition options

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### Colonisation by numbers

- minoritise indigenous rights by
- rename as indigenous “minorities”
- rights “less valid” than “total population”
- total population is a misnomer, usually a proxy for numerically dominant group

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### Colonisation by numbers

- if there are disparities in outcomes between indigenous and non-indigenous populations
- these can be obscured
- data of numerically dominant is privileged
- fails to provide evidence for interventions
- complicit in societal inequity and white privilege

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### Colonisation by numbers

- who has the power to name who is indigenous and how we are defined
- examine the history of how indigenous peoples have been and are defined in official statistics to describe the colonial agenda of governments

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### Health Information

- potential to support indigenous rights, need

#### **ethnicity data that is**

- good quality
- complete
- comprehensive
- continuous through time

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- need further discussion on:

- ethics
- ownership and intellectual property
- access and control
- analysis and voice (non-deficit)
- planned & determined by

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- need further discussion on ethnicity data
- representation of rights
- power to define self
- non-indigenous reluctance to affirm rights
- illustrates how indigenous peoples are valued
- theoretical (and historical) context

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### Preventing Propaganda

- the description and representation of data identifies the often unspoken (unthinking) theoretical framework of the analyst
- deficit model and racist representations of indigenous people are propaganda

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### Preventing Discrimination

- obvious inequalities (if data available)
- differential access to the goods, services and opportunities of society by ethnicity
- non-indigenous privilege not examined or not named
- researchers play a role in the silence and therefore help maintain the privilege

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### Summary

- see in big picture context – better world
- equity
- theory, theory, theory
- indigenous rights
  - Ethnicity data, equal voice, liberating non- colonising analysis

