

A Comparative Analysis of Research Guidelines to Inform Genomic Research in Indigenous Communities



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Acknowledgements

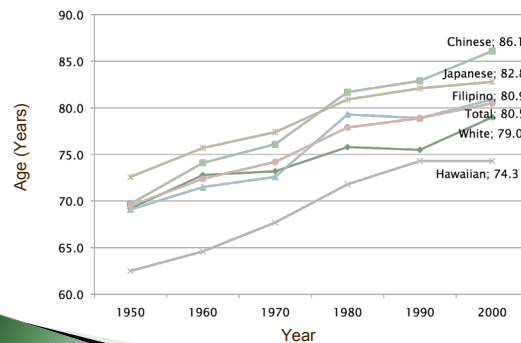
- ▶ Committee Members:
 - Jay Maddock, PhD
 - Maile Tauli'i, PhD, MPH
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Why is Genomic Research important with Indigenous Peoples?



Life Expectancy at Birth by Ethnicity, 1950-2000



Sources: Park, Braun, Horuchi, Tottori, Onaka. Longevity Disparities in Multiethnic Hawaii: An Analysis of 2000 Life Tables. Public Health Reports 2009, Vol 24.

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Ideal Candidates....

- ▶ Isolated populations are ideal for genetic studies
 - Genes are easier to study because relatively homogenous
 - Homogeneity may lead to immunity against certain genetic diseases, thus providing important insight into the treatment of those diseases
 - Example: Native Hawaiian community

Source: Alice Hsieh, A Nation's Genes for a Cure to Cancer: Evolving Ethical, Social and Legal Issues Regarding Population Genetic Databases, 37 Colum. J. L. & Soc. PROBS. 359, 370 (2004).

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Importance of Genomic Research

- ▶ To understand health disparities that exist in Indigenous populations
- ▶ Indigenous populations are genetically unique and targets for research



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Native Hawaiian Genome Project

- ▶ 2003, the University of Hawaii proposed patenting the Native Hawaiian genome with the purpose of generating both economic- and health-related benefits for the Native Hawaiian people
- ▶ Proposal was strongly opposed by the Native Hawaiian community, who viewed it as an act of Western culture's invasion and destruction of Indigenous peoples
- ▶ Resolution – Hawaiian Civic Clubs
 - **Cease and Desist - Until such the Native Hawaiian people have been consulted and given their full, prior and informed consent**

Specific Aims of My Research

- ▶ **Specific Aim 1:** Conduct an international review and comparison of Indigenous research guidelines related to genetic research.
- ▶ **Specific Aim 2:** Using data from specific aim 1, develop policy recommendations for Indigenous communities interested in creating formal policies around the use of genetic information and protection of biological samples.

Methods

- ▶ A comparative analysis was conducted using key resources to identify best research practices and recommendations of Indigenous groups among four countries: Canada, New Zealand, Australia and the United States
- ▶ Current international Indigenous guidelines identified
- ▶ Political relationships examined
- ▶ Resources were provided via the Native Hawaiian Epidemiology Center

Aim 1 Results- International Review

Table 1. Timeline of Indigenous Research Guidelines developed throughout United States, Australia, Canada and New Zealand.

Title	Date	Author
Indigenous Research Protection Act (US)	2000	Indigenous Peoples Council on Biocolonialism (IPCB)
Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (AUS)	2003	National Health and Medical Research Council (NHMRC)
Guidelines for Health Research Involving Aboriginal People (CA)	2007	Canadian Institutes of Health Research (CIHR)
Guidelines for Researchers on Health Research Involving Maori (NZ)	2008	Health Research Council of New Zealand (HRCNZ)

Aim 2 Results- Comparative Analysis

▶ See Handout:

Table 2
Comparative Analysis of Indigenous Research Guidelines Concerning Genetic Research Across Four Countries

	Canada	New Zealand	Australia	United States
Community Consultation				
In protocol development	✓	✓	✓	✓
Before collection of samples	✓	✓	✓	✓
Emphasizes respect for cultural differences	✓	✓	✓	✓
Formal community approval required	✓	✓	✓	✓
Sample Collection and Informed Consent				
Done in a culturally sensitive manner	✓	✓	✓	✓
Discussion of a collective harm (e.g. group discrim) as part of informed consent process	✓	✓	✓	✓
Use and Storage of Biological Materials				
Formal uses defined prior to sample collection	✓	✓	✓	✓
Provisions for withdrawal of samples (IW or CW)		IW, CW		CW
Discussion of secondary uses with contributors (DI or DC)		DI, DC		DC
Secondary uses require community approval	✓	✓	✓	✓
Privatization of Research Data				
Should benefit contributing population	✓	✓	✓	✓
Clear position on commercial applications	✓	✓	✓	✓
Post-Research Obligations				
Ongoing research updates to participating communities	✓	✓	✓	✓
Community review of study findings before release	✓	✓	✓	✓
Need to develop local capacities	✓	✓	✓	✓

Bolded terms = Leading principles of concern to Indigenous peoples regarding genetic research
 ✓ = Identifies a sub-principle within a country's guideline
 IW = Individual withdrawal
 CW = Community withdrawal
 DI = Discussion held with individual
 DC = Discussion held with community

Limitations

- ▶ Recognizing significant crossovers due to wording and labeling differences
- ▶ Assessment of relevancy and merit of guidelines
- ▶ Selection criteria for guidelines is limited to those created by English-speaking countries

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Discussion & Policy Implications

- ▶ Genomic research is a growing field
- ▶ Indigenous peoples continue to experience harm
- ▶ Policy enforcement regarding secondary uses of data, withdrawal of samples, and benefit sharing
- ▶ Clearinghouse of guidelines and resources may be helpful

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Discussion & Policy Implications

- ▶ The comparative analysis comprise principles necessary to meet:
 - 1) Ethical requirements of the research process
 - 2) Utilization and governance over information obtained from research
- ▶ The comparative analysis suggests that principles established for the use and storage of biological materials needs to ensure:
 - 1) Research is first carried out ethically
 - 2) Research participants are not harmed by involvement in a biobank

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Recommendations

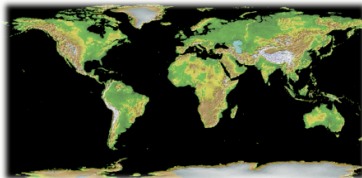
1. **Development:** Indigenous research guidelines concerning the use of genetic information and protection of biological samples throughout New Zealand, Australia and the United States.
2. **Trust:** Recognizing "trust" as a principle within Indigenous research guidelines.
3. **Implementation:** Enforcement of policy or law by repercussive actions on those who violate the rights of Indigenous peoples through research.

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Take Home Message

"The measure of a country's greatness should be based on how well it cares for its most vulnerable populations."

-Mahatma Ghandi



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Mahalo!

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**References Available Upon Request

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