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

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Why is Genomic Research important with Indigenous Peoples?

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

Importance of Genomic Research

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

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<thead>
<tr>
<th>Title</th>
<th>Date</th>
<th>Author</th>
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<tbody>
<tr>
<td>Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (AUS)</td>
<td>2003</td>
<td>National Health and Medical Research Council (NHMRC)</td>
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<tr>
<td>Guidelines for Health Research Involving Aboriginal People (CA)</td>
<td>2007</td>
<td>Canadian Institutes of Health Research (CIHR)</td>
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<tr>
<td>Guidelines for Researchers on Health Research Involving Maori (NZ)</td>
<td>2008</td>
<td>Health Research Council of New Zealand (HRCNZ)</td>
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Aim 2 Results- Comparative Analysis

- See Handout:
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

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

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

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.
3. Implementation: Enforcement of policy or law by repercussive actions on those who violate the rights of Indigenous peoples through research.

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