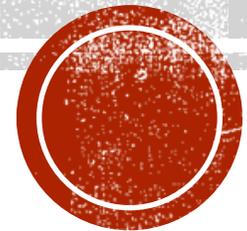


DEVELOPING BEST PRACTICE BIOBANKING WITH INDIGENOUS PEOPLES

ISBER Conference 2014

Orlando, Florida



INDIGENOUS GENOMICS ALLIANCE

- Emerged from University of Washington
- Network of Indigenous researchers from USA, Canada, Australia, New Zealand interested in best practice for researchers working with indigenous communities
 - Most researchers working with indigenous communities are neither indigenous nor have good knowledge of indigenous values, practices and world views
 - Negative experiences eg., Havusupai (USA), Warrior gene (NZ)



EVIDENCE BASED BIOBANKING

- Many Indigenous researchers and communities are concerned about biobanking and genomic research
- Growing movement amongst Indigenous people for self-determination and the regaining control over resources, including genetic and intellectual resources
- Recognition that research creates opportunities for researchers (unique genetic variants) and communities (contribution to indigenous health needs)
- (C)ELSI – is not about a tail or a dog but the remembering that behind each sample is a human and ‘all their relations’

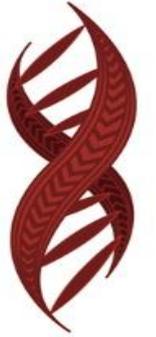


CURRENT RECOMMENDATION

- ***Consideration of Perspectives of Communities, Populations, Ethnic and Social Groups Best Practice***
- ***When research focuses on a particular community it is best to seek input from representatives of the group on relevant aspects of the **design of the study**, the **consent process**, appropriate uses of specimens and **dissemination of collective research findings**. (ISBER, 2012)***



NEW ZEALAND



- **Research: Te Mata Ira – Culturally Informed Guidelines for Biobanking and Genomic Research (9 discussion groups, n= 90+)**
 - Relationships with researchers/biobanks
 - Relationships with tissue/data
 - Consultation, consent and control
- **Practice: Christchurch Cancer Society Tissue Bank & Middlemore Tissue Bank**
 - Guidelines for handling samples
 - Guidelines for disposal and retention of samples
 - On-going relationships with Maori groups
 - Cultural advisors and practices

The development of guidelines for handling samples and specimens collected for research involving Maori. The New Zealand Medical Journal. Vol 120 No 1264.



CANADA

- **Research: DNA on Loan**
 - Alignment with Aboriginal research priorities
 - Integrated governance
 - Participatory processes
- **Policy: Canada's Tri-Council Policy Statement – Ethical Conduct for Research Involving Humans**
 - Research partnerships & benefit sharing
 - Consent – individual and collective
 - Protection of cultural knowledge
 - Use of tissue and data

Arbour, L., & Cook, D. (2006). DNA on Loan: Issues to Consider when Carrying out Genetic Research with Aboriginal Families and Communities. *Community Genetics* (9) 153-160.



ALASKA

- **Research: Alaska Native People's perceptions and expectations of Research with biological samples (29 focus groups, n=178)**
 - Greater disclosure of information beyond consent, results dissemination
 - Intent of researchers, Specifics of storage and destruction, Clear processes of consent
 - Increasing trust by being responsive to community expectations
- **Research: Tribal perspectives on Data Sharing (Exploring pathways to trust mtg)**
 - Protecting ownership interests in data
 - Mechanisms for consultation
 - Mechanisms for dissemination of information
 - Input into secondary use of data

Hiratsuka, VY., Brown, JK., Hoeft, TJ. & Dillard, DA. (2012). Alaska Native peoples perceptions, understandings and expectations for Research involving biological specimens. Int Journal of Circumpolar Health.



HAWAII

- Research: Explored Native Hawaiian perceptions and expectations of biobanking
- Key themes
 - Biobank governance by Native Hawaiian community
 - Research transparency
 - Priority of Native Hawaiian Health concerns
 - Leadership by Native Hawaiian researchers
 - Re-consenting for each use
 - Education of Native Hawaiian communities
- Practice: Queen Liliokalani Hospital
 - Staged consent process for surgical tissue
 - Consent to take samples, consent to use samples after 6 months

Taualii, M., Davis, EL., Braun, KL., Tsark, JU., Brown, N., Hudson, M. & Burke, W. (2014). Native Hawaiian Views on Biobanking. Journal of Cancer Education. DOI 10.1007/s13187-014-0638-6



AUSTRALIA

- Practice: Establishment of Indigenous Biorespository (SAMHRI) focused on:
- Protection of Indigenous cultural integrity, knowledge and collective information (ethical and legal);
- Indigenous governance, stewardship, custodianship of biological samples and data, and making determinations as to access, utilization and future use where relevant and appropriate;
- Representing community interests, particularly as they relate to principles of self-determination, free prior and informed consent, identifying impacts and negotiating benefit/s (scientific and financial); and
- Development of educational/genomic literacy materials for Indigenous communities and the research sector.



COMMONALITIES

- Respectful relationships
- Community consultation (consent/mandate)
- Individual consent / re-consent
- Rights & interests in relation to samples and data
- Governance (of samples and data)
- Inclusion and training of indigenous researchers
- Review publications and access results
- Development of ethics guidelines
- Shift towards regulatory and policy tools



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National Congress of American Indians



American Indian & Alaska Native GENETICS RESOURCE CENTER

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What's Hot

- ▶ [Quick Tips for Tribal Leaders](#)
- ▶ About Genetics
- ▶ Protecting Your Community
- ▶ Examples from Tribes
- ▶ Tribal Enrollment & DNA Testing

[Quick Tips for Tribal Leaders](#)

A summary toolkit providing a quick overview of issues related to genetics research in tribal communities.



Genetics Research and American Indian and Alaska Native Communities

Genetics research is a fast-growing and complicated area. American Indian/Alaska Native (AI/AN) tribal leaders and citizens have raised many questions and concerns about genetics research. They have also expressed an interest in learning more about the science behind genetics and how other tribal communities are making decisions related to genetics research. This resource guide serves to answer these questions, to highlight cases that describe how some tribes are thinking about genetics research, and to provide information and tools for tribes and citizens as they consider their own stances on genetics research. Each person, family, and community is unique and therefore will have a different set of considerations regarding research.

How Do We Decide?

A Guide for American Indian/Alaska Native Communities

The interactive decision guides provide a set of interactive questions to help you reflect on your feelings regarding research.

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GENETICS SYMPOSIUM: A SPECTRUM OF PERSPECTIVES: NATIVE PEOPLES & GENETIC RESEARCH

- June 23rd 2014
- National Museum of the American Indian, Washington DC
- NCAI, NHGRI and NMAI Collaboration as part of 'Genome: Unlocking Lifes Code'

- Can genetics research improve Native health?
- The ethics of blood
- Genomics & ancestry: Ethics, origins, and policy
- Insights from the field: Next generation Native researchers



INDIGENOUS 'RECOMMENDATION'

- When biobanks hold indigenous tissue and data, the biobank should ensure that, when it is used for research, appropriate consultation and communication with indigenous communities takes place.
- Indigenous representation on governance structures and inclusion within processes for approving the release of indigenous tissue and data is recommended.



SUMMARY FROM AN INDIGENOUS PERSPECTIVE: COULD DO BETTER!

- Understand cultural & political context
 - Indigenous rights and interests are different from those of ethnic/social groups
 - Resource control & identity politics
- Relationship with Tissue & Data
- Process of Consent and Consultation
- Governance of the Resource & the Research
- Self determination
 - Objection to biobanking practices and blanket consents that remove levels of participation and control from indigenous communities
 - Development of indigenous biorepositories

