When Science Outpaces Native Political Will:

The relationship of science to emerging indigenous partnerships

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Native Perspectives on Research

• Native Case Studies: Alaska & Hawai‘i

• ‘New’ Era of Community Engagement & Participatory Research

• Native Wisdom – Scientific Evidence

• Research that Benefits Native People
An issue of trust

• Native Americans have trust issues with both research and the Federal government
• Native sovereignty
• Do the benefits to the tribe outweigh trust issues?
Specimen Bank: Case in Point

• The collection of biological materials
• Use and consent issues
• Benefits:
  – pre diagnostic markers
• Prevalence (e.g. Helicobacter pylori)
  – Individual identification
Specimen Bank: Case in Point

- **Management:** IHS, CDC, AK Native Tribal Health Organizations and State of Alaska (Public Health) Working Group

- **Policies for the future**
  - Consent to be in a research study
  - Consent to store and test samples
  - Option for individuals to opt out of stored specimens
Tribal questions

• Who owns the data?
• How will it be used?
• Do tribes have control of the final product (i.e., publications)?
• Who has access to these data?
A Woman’s Risk of Getting Breast Cancer Increases with Age.

Risk is 1 in:

>28,000  19,608  622  93  33  17  11  9
Consent issues

• How was/is consent obtained?

• Ethics of the researchers

• Ethics education for Native entities

• Cross-cultural training of researchers
Empowering Tribes

• Training of individuals to do research in their communities

• Explaining of benefits to tribes

• Identifying PI’s to do this research

• Utilizing focus groups
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Who are Native Hawaiians?

• ~500 AD: indigenous people of Hawai'i
• 1778: James Cook arrived
• 1893: Illegal overthrow of Hawaiian Kingdom by American businessmen
Queen Liliʻuokalani (1838-1917)  
Reigned 1891 - 1893  

“I do under this protest, and impelled by said force, yield my authority until . . . the United States shall . . . undo the action of its representatives and reinstate me in the authority which I claim as the constitutional sovereign of the Hawaiian Islands.”  

January 17, 1893
Native Hawaiians continue to struggle to recover their LAND and SOVEREIGNTY.
Malama Puʻuwai Study
A Research Partnership: Department of Native Hawaiian Health & Queens Medical Center
The Malama Pu'uwai Project

**Mission**: to address and reduce cardiovascular disparities, specifically heart failure, in Native Hawaiians and other Pacific Island Peoples
- Research Studies, Training and Community Engagement

- Consists of 4 interrelated studies on heart failure among Native Hawaiians & Other Pacific Islanders
  - Randomized Control Trial
  - Community Health Worker Echo
  - Ethnic differences in Heart Failure
  - Family Heart Health History Study

NIH-NHLBI U01 HL079163
‘Ohana (Family) Heart Health History

• **Purpose:** Identify & collect detailed family health histories in Native Hawaiian patients with diagnosed heart failure.

• **Research Question:** Are there inherited forms of cardiomyopathy that might explain excess heart disease?
‘Ohana Heart Health History Study

- Native Hawaiian Probands with Diagnosed Heart Failure Identified & Enrolled (N=10)

- Detailed Family Histories were constructed for each family.
(Somewhat) Unexpected Findings: Inherited Cardiomyopathy in Native Hawaiians

• Predominant pattern of inheritance – **autosomal dominant**
  – Patterns of inheritance – allows genetic risk stratification

• Automatic Implantable Cardiac Defibrillator – Life-saving treatment in diagnosed cardiomyopathy
  – Non-invasive method for screening family members

• How best to inform family members about this potentially life-saving treatment for a genetic disease?
Currently: ‘Ohana (Family) Heart Health History Study

• Specific Aim completed

• Ongoing discussion with families involved with the study about the meaning of their results
  – Referral to genetic counseling if desired

• Goal: Seek guidance & meaning of study to families (and larger community – native & clinical)

Scientific/Research Pause to allow for families, native & clinical communities to learn of results & suggest future steps
John A. Burns School of Medicine

at University of Hawai‘i
So the question arises…

How to do Research with Native Communities?

Some thoughts worth considering…
Community Engagement & Participatory Research: *Beyond Cross-cultural Communications*

Researchers need a stronger understanding of...

- Meaningful partnerships with communities
- Context – community, cultural, literacy
- Trust – building, sustaining, strengthening
- Power-sharing – knowledge, budget, resources
- Community needs – understand benefit of research

AND Practical Experience / Mentorship on achieving them
What does Community Engagement *Mean*?

What is *Meaningful* Community Engagement?

... at it’s HEART is...

Intersection of the complementary efforts of members of the lay community, health practitioners & medical & public health researchers to improve health.

CTSA Consortium’s Community Engagement Key Function Committee Workshop Summary 2008
Key Ethical Issues in Native Communities

- Preparing for research in Native communities
- Developing the collaboration or partnership
- Informed consent issues
- Community knowledge collection
- Research data management
- Sustainability of research efforts

Quigley, Health Educ Behav Apr 2006
Sustainability is KEY for Native Communities

• Sustainability for Communities means tangible benefits resulting from the study findings
  – How will this benefit our community?
  – Will we be teaching this new knowledge to the next generation?
  – Will there be better ways to keep our people healthy?

• Researchers need to engage in ACTIVE Listening
  – able to touch the essence of what the family/community needs may be.