Alaska Native People’s Perspectives On Biospecimen Collection and Storage for Research: A Focus On The Alaska Area Specimen Bank

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65,000 voices
Points of Reference

Citations:

Study Purpose

- Explore views of biobanking among Alaska Native community members and leaders across Alaska using community based participatory research (CBPR) approach.
Methods

- The Alaska Area Specimen Bank Working Group was engaged to develop and implement the study over a 7 month period.
- Approached 25 tribal health organizations (THOs) to partner and guide the study in their regions.
- Community liaisons were hired to lead study recruitment.
- After 18 months of engagement, 14 THOs gave approval.
- 29 focus groups were conducted across locations -- 82 community members and 81 tribal leaders.
Methods

- Participants were asked several types of questions:
  - General thoughts about collecting and storing biospecimens for research
  - Information they would want when deciding whether to join a study in which biospecimens were collected and possibly stored
  - Opinions about what to do in specific situations such as when a person who contributed a specimen passes away
Results

- Five themes associated with views about biobanking
- Expectations related to potential participation
Theme 1: Prior Experiences with Research and Medical Community

- Negative research examples like Barrow Alcohol Study
- History of poor care with little explanation provided
- Research improvements and benefits also mentioned

“…I remember the Hepatitis B program when it came through. And I remember walking my kids – because we didn’t own a vehicle – down to the clinic and participating and not knowing anything. But it’s a good thing.”
Theme 2: Stigmatization and Harm Potential, Relevance, & Applicability

- Data could stigmatize or harm through questioning blood quantum, rights, or dismissing creation stories
  - “Well they have this disease, or they’re carriers of that.”
- Relevance and applicability when data aggregated and focii of research not community-driven
  - “We’re... not part of that culture anymore than New Jersey is of Louisiana.”
  - “If we have some way of knowing that it would help better Alaska Native people in some way, in terms of diabetes or you know those kinds of diseases, then I would be more willing to give up a sample because I think there are certain diseases that seem prevalent in Alaska Native cultures.”
Theme 3: Governmental & Cultural Change

- Changes in governing structures after Alaska Native Claims Settlement Act could leave people vulnerable
  - “It’s easier to focus on somebody if we’re gonna do a study they don’t have the government, the protection. There’s not even a developed state yet.”

Theme 4: Future Research & Technology Advances

- Concerns about duplication of cells, cloning particularly without express permission
  - “Tissue research is advancing fast... there’s a lot of places that these samples could be used”
  - “…you would have to sign a consent form because people don’t believe in having their cells and so forth duplicated”
Theme 5: Benefit for Future Generations

- Perceived harms were paired with potential benefits particularly in future generations
  - “I think of future generations. I’m a grandmother. I have a history of cancer. So research would help my future generation. But it’s how this is collected that I’m concerned about. Make sure you have consent forms to be able to use that research at all times... And ensure that it’s never used in any way that would harm the genealogy of my family.”
Expectations

- Researcher seeking beneficience not personal gain
  - Motivation of researcher, awareness of community context, rationale and intent in collecting and storing biospecimens, potential career advancement as well as financial gains
  - “I want to know exactly what the people that are doing the research, exactly what their true intentions are and I think that sometimes their true intentions aren’t really given... they don’t fully explain what they need that information for.”
Expectations

- Extensive consenting process
  - Participants receive information on research ethics and specifics of specimen storage, care, and future use
  - Documents include:
    - Date of destruction and destruction process
    - Any sharing of information or specimens with another organization
  - Present options for future use of specimens
    - Re-consent for each use
    - Permission for certain types of studies
    - Destruction or return upon death
Expectations

- Return of results
  - Share progress and results to individual participants and communities during and after the study
  - Return individual results or how individual contribution benefited the overall study
  - Review by community leaders prior to public release
  - Share potential implications of findings
    - “...a lot of the researchers were always promising verbally that they were going to share the information with you and... more than half the time they never see the results of the data after they leave your community. That’s part of the reason why a lot of the Natives in small communities don’t trust the researchers.”
Thank You!

Qağaasakung
Aleut

Quyanaq
Inupiaq

‘Awa'ahdah
Eyak

Mahsi'
Gwich’in Athabascan

Igamsiqanaghghalek
Siberian Yupik

Háw'aa
Haida

Quyana
Yup’ik

Way Dankoo
Tsimshian

Gunalchéesh
Tlingit

Tsin’aen
Ahtna Athabascan

Quyanaa
Alutiiq

Chin’an
Dena’ina Athabascan