



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

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Points of Reference

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Alaska Native people's perceptions, understandings, and expectations for research involving biological specimens

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Objectives. Members of racially and ethnically diverse groups have been persistently underrepresented in biomedical research in general, possibly due to mistrust with the medical and research community. This article describes the perceptions, understandings, and expectations of Alaska Native people about research involving the collection and storage of biological specimens.

Study design. Stratified focus groups.

Methods. Twenty-nine focus groups with Alaska Native people (n = 178) were held in 14 locations using a semi-structured moderator guide. ATLAS.ti was used for thematic analysis through iterative readings and coding. Alaska Native peoples' perceptions, understandings, and expectations of researcher beneficence, informed consent processes, and provision of research findings were elicited.

Results and conclusions. Alaska Native people desired extensive disclosure of information beyond that typically provided in consent and results dissemination processes. Information germane to the motivation and intent of researchers and specifics of specimen storage and destruction were specifically requested. A clear and extensive process of informed consent and continued improvements in sharing results may enhance the transparency of research intent, conduct, and use of obtained results among Alaska Native people. Meeting expectations may improve relationships between researchers and the Alaska Native population which could result in increased research participation. Our findings offer a guide for researchers and communities when planning and implementing research with biological specimens.

Keywords: Alaska; Indians; North America; focus groups research ethics; informed consent; results dissemination

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Racially and ethnically diverse people have been persistently underrepresented in biomedical research and specifically in genomic research (1-8). American Indian (AI) and Alaska Native (AN) people have a documented history of mistrust with research which may partially account for lower levels of participation in research (1,9,10). The results of a recent ethical misconduct case with the Havasupai tribe where blood samples were in multiple research projects that were far afield of the study purpose within the informed consent further underscore the potential incongruence between AI/AN expectations of research and commonly accepted research practices with biological specimens (11). Since the signing of the Indian Self Determination Act (Public Law 93-638) which made it possible for American Indian and Alaska Native tribes to enter into funding agreements and self-govern health services,

AI/AN tribes and groups are increasingly assuming ownership and control of research with people in their communities. For instance, in Alaska, Alaska Native health research requires approval by at least 1 and often 2 tribal leadership groups in addition to Institutional Review Board approval with review consisting of detailed evaluation of proposals, recruitment materials, consent forms, and result dissemination plans. Given the limited empiric investigations of the understanding, perceptions, and expectations of AI/ANs when biological specimens are collected and stored for research, there is the potential for research processes to be incongruent with what AI/ANs need in order to participate in research.

A collection of stored samples dating back to the 1940s from US-funded Alaska research projects resides in the Alaska Area Specimen Bank (AASB) in Anchorage, Alaska. Following the Indian Self Determination

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Views of Biobanking Research Among Alaska Native People: The Role of Community Context

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Abstract

Background: Research using stored clinical data and samples held in biobanks has potential to address health disparities in minority communities. However, ethical and cultural considerations about use of these samples for research warrant attention. Literature about how Alaska Native people (AN) view biobanking research consists largely of theoretical papers and position statements with limited systematic information gathered from a broad range of ANs.

Objectives: To explore the views of biobanking research among AN community members and leaders across Alaska using a community-based participatory research approach with tribal and federal partners.

Methods: We approached tribal health organizations (THOs) to partner and guide the study in their regions. Community liaisons were hired to lead study recruitment. Twenty-nine focus groups were conducted in 14 locations with participation from 82 community members and 81 tribal leaders. Data were analyzed using a grounded theory approach.

Results: We identified five themes that contributed to participants' views on biobanking: (1) Prior experiences with research and medical care, (2) stigmatizations, relevance, and applicability, (3) effects of governmental and cultural change, (4) concerns about unknown capability of future technologies, and (5) benefit for future generations. Respondents raised AN-specific cultural concerns along with global ethical concerns alongside the potential promise of research in improving AN health.

Conclusions: This study offers considerations for researchers partnering with AN communities when planning research and public health surveillance projects. Findings also have implications for other minority communities harmed by past research and other societal changes.

Keywords

Community-based participatory research, community health partnerships, health disparities, health care quality access and evaluation, ethics

Research with stored biological samples and associated clinical data has the potential to address health disparities in minority communities. However, minority community members have been persistently underrepresented in biomedical research,^{1,2} most markedly in genomic research.^{3,4} As a result, the application of project findings in addressing health disparities may be limited in communities where great disparities exist.⁵ The experiences of American Indian (AI) and AN peoples^{6,7} clearly illustrate the tension between the recognition of the potential research holds to

improve health and the hesitance of some communities to participate in research, given mistrust and apprehension.

Prior published work about biobanking research with AN and other indigenous peoples has largely been theoretical or position statements by researchers or tribal leaders.^{8,9,10} Three studies have systematically gathered information from AN/AI community members on biobanking research.^{11,20,21} To date, there are no in-depth accounts of AN perspectives, despite a rich history of biobanking research.

A collection of stored samples dating back to the 1940s from

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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



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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.”



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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 ”*



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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.”*



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Expectations

- Researcher seeking beneficence 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.”*



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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!

Qaġaasakung

Aleut

Quyanaq

Inupiaq

'Awa'ahdah

Eyak

Mahsi'

Gwich'in Athabascan

Igamsiqanaghalek

Siberian Yupik

Háw'aa

Haida

Quyana

Yup'ik

Way Dankoo

Tsimshian

Gunalchéesh

Tlingit

Tsin'aen

Ahtna Athabascan

Quyanaa

Alutiiq

Chin'an

Dena'ina Athabascan



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