

American Indian/Alaska Native Community Engagement Preferences and Tribal Code Requirements

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AMAZING STORIES
BEING WRITTEN EVERY DAY.

American Indian/Alaska Native Peoples

- 574 federally recognized Tribes in 37 states
- 5.2 million American Indian and Alaska Native (AI/AN) people
(as of January 2020)
- AI/AN people have long experienced lower health status when compared with other Americans
- AI/AN tribes are sovereign nations with an inherent right to self-determination, including deciding whether and how health research may be conducted

TEN UNIVERSAL VALUES

SHOW RESPECT TO OTHERS

Each Person Has a Special Gift

SHARE WHAT YOU HAVE

Giving Makes You Richer

KNOW WHO YOU ARE

You Are a Reflection on Your Family

ACCEPT WHAT LIFE BRINGS

You Cannot Control Many Things

HAVE PATIENCE

Some Things Cannot Be Rushed

LIVE CAREFULLY

What You Do Will Come Back to You

TAKE CARE OF OTHERS

You Cannot Live without Them

HONOR YOUR ELDER

They Show You the Way in Life

PRAY FOR GUIDANCE

Many Things Are Not Known

SEE CONNECTIONS

All Things Are Related

-Taken from the Alaska Native Knowledge Network

Defining Community Engagement

Community engagement is the process of working collaboratively with a community to address issues that impact the well-being of the group.

Activities within the process of community engagement include:

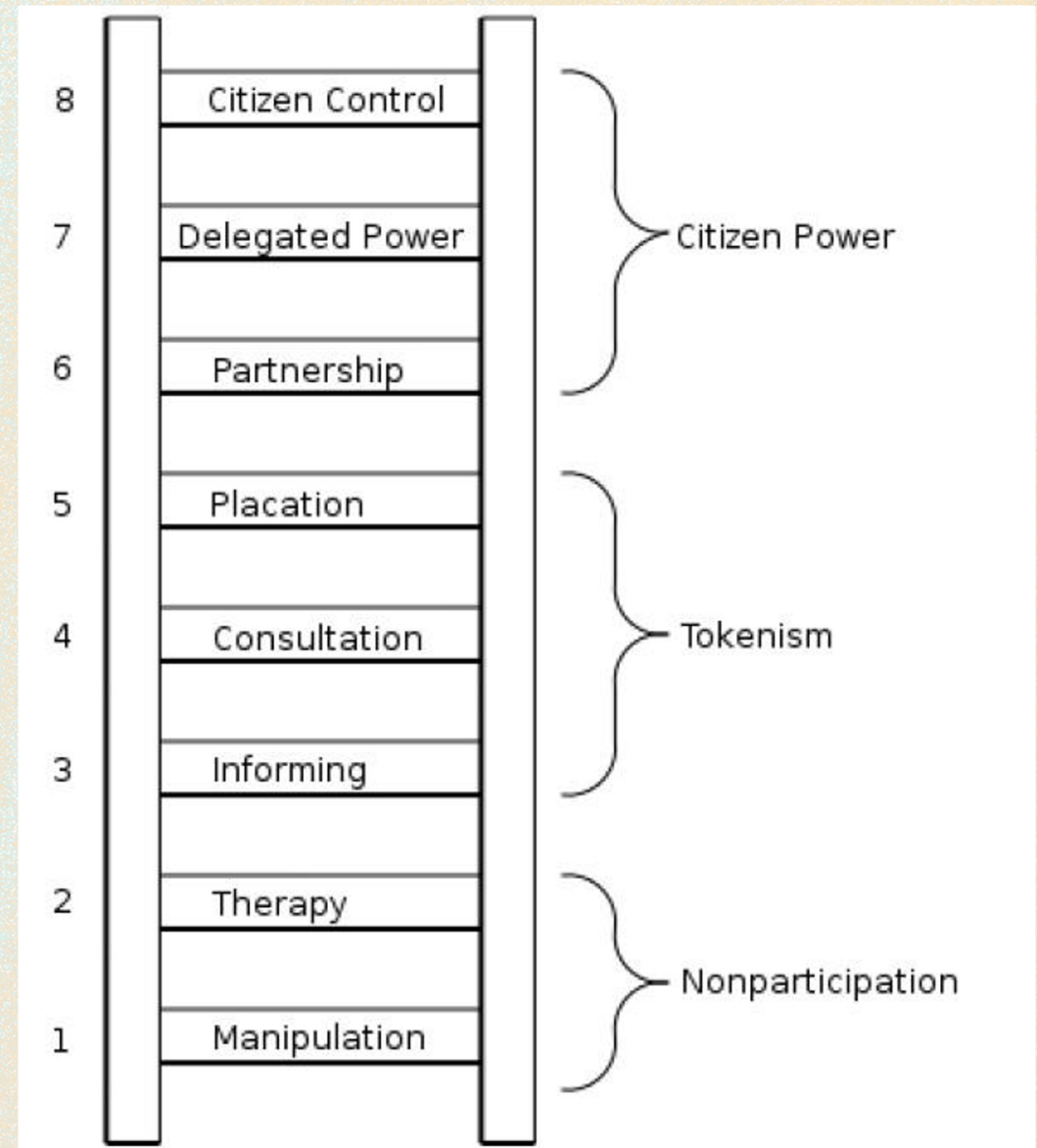
- ▶ Proactively seeking out community values, concerns and aspirations;
- ▶ Incorporating those values, concerns and aspirations into a decision-making process or processes; and
- ▶ Establishes an ongoing partnership with the community to ensure that the community's priorities and values continue to shape services and the service system.

Terms

- ▶ **Community:** A group of people who share a common place, experience or interest.
- ▶ **Partnerships:** Alliances that are used to improve the health of a community.
- ▶ **Community capacity:** The ability of community members to make a difference over time and across different issues.
- ▶ **Community change:** Developing a new program (or modifying an existing one), bringing about a change in policy, or adjusting a practice related to the group's mission.

Ladder of Participation

- ▶ Arnstein (1969) described a ladder of participation
- ▶ The ladder is a guide to seeing who has power when important decisions are being made
- ▶ How might we use the Ladder of Participation in planning for future community engagement?



In brief- How we do community engagement...

- ▶ Form a team to design the research question(s) and all aspects of the project
- ▶ Collaboratively create a plan to define and reach goals
- ▶ Active participation during ALL phases:
 - ▶ Conceptualization-What's important and to whom?
 - ▶ Conduct of project- How do we manage the process?
Resources? Conflicts?
 - ▶ Dissemination of project- Sharing our findings

What does community engagement look like?

- Community advisory boards
- Development of research ideas from community priorities
- Hiring of community members as research team members
- Community member consultants/subject matter experts
- Community member co-development of data collection instruments
- Community member feedback on analysis processes, preliminary results and dissemination processes
- Community directed dissemination processes and products
- Community co-presenters/authors

Engagement methods

- ▶ There is no simple solution or one fit all approach to identifying an effective engagement method.
- ▶ To be most effective it will often be necessary to combine a range of complementary methods.

Examples:

- ▶ Public meetings
- ▶ Community mapping
- ▶ Round table consensus building
- ▶ Photovoice
- ▶ Surveys
- ▶ Citizen juries
- ▶ Focus groups
- ▶ Workshops
- ▶ Opinion polls
- ▶ Interviews
- ▶ Public deliberation

Ethical and Cultural Implications of Specimen Banking Among Alaska Native People



Hiratsuka, V., Brown, J., Lockhart, A., & *Dillard, D.* (2012). Views of biobanking research among Alaska Native people: The role of community context. *Progress in Community Health Partnerships: Research, Education, and Action*, 6(2), 131-9.

Hiratsuka, V., Brown, J. Hoeft, T., & *Dillard, D A.* (2012). Alaska Native people's perceptions, understandings, and expectations for research involving biological specimens. *International Journal of Circumpolar Health*, 71:18642 – <http://dx.doi.org/10.3402/ijch.v71i0.18642>. PMID: PMC3417706.

Ethical, Legal and Social Implications (ELSI) Research with Alaska Native People

- Community Engaged Research Towards Precision Medicine
 - Support Precision Medicine research (PMR) through culturally respectful dialogue, empiric data collection, and deliberation with rural and urban AIAN community members and tribal representatives in Alaska and Montana.
 - Address three complex and important challenges: (1) alignment of PMR with tribal health priorities; (2) return of PMR results to participants and communities; and (3) data stewardship
- Center on American Indian and Alaska Native Genomic Research
 - Create an interdisciplinary center capable of supporting innovative research and education of the next generation of researchers poised to harness exciting innovations in biomedicine to the needs of AIAN communities

Participatory practices in empiric ELSI projects:

- Tribal consultation/NIH Tribal Advisory Board
- Public deliberation
- Community forums
- Subject matter expert workshops
- Administrative practices—power sharing & capacity building

UNIVERSITY-COMMUNITY COLLABORATIONS PORTAL

Power Sharing, Capacity Building, and Evolving Roles in ELSI: The Center for the Ethics of Indigenous Genomic Research

Jessica Blanchard¹, Vanessa Hiratsuka², Julie A. Beans², Justin Lund¹, Bobby Sauni³, Michael Pee⁴

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CASE COMMENTARIES

Being in Good Community: Engagement in Support of Indigenous Sovereignty

Jessica Blanchard^a and Vanessa Hiratsuka^b

^aUniversity of Oklahoma; ^bSouthcentral Foundation

Persistent, unimpaired, and have kept many of our Indigenous moves toward reflects on key implications of community participation in empirical research. Transparency shifts away from traditional features of community partnership: 1 that promote inner sites. The of our Center plasticity of 1 and strengthen

Keywords: American research; ELSI

Persistent, unimpaired, and have kept many of our Indigenous moves toward reflects on key implications of community participation in empirical research. Transparency shifts away from traditional features of community partnership: 1 that promote inner sites. The of our Center plasticity of 1 and strengthen

(Hiratsuka et al. of specific genetic development: some tribal consultation and control et al., 2011; Dr. 2013; Morton et

Authentic communities eighty over r Native (AI/AN) unique government expectations research by si (Claw et al. 21 and Burke 201

Keywords: Am research; ELSI

Meaningful engagement of tribal health organizations is responsible and ethical research important to advancements populations not meaningfully benefit from the outcomes historically been underrepresentation in genomic research based on past abuse ownership, and cultural context research. Working together Research Institute and two Southcentral Foundation and cosponsored a workshop in Ju discussion, strengthen relation

INTRC

Meaningful engagement of tribal health organizations of socially responsible and Native people have historical genetic and genomic research. In 2018, two Alaska Native central Foundation (SCF) and (ANHB)—cosponsored a workshop the National Human Genome (ANHB)—cosponsored a workshop the National Human Genome the goal of the workshop we and opportunities for en

CONTACT Jessica Bl

Open

Alaska Native genomic research: perspectives from Alaska Native leaders, federal staff, and biomedical researchers

Vanessa Y. Hiratsuka, Sara Chazotte, Denise A. Dillard, PhD, Andrea C. Beaudette, Francine C. Gachupin

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REVIEW ARTICLE | Genetics in Medicine

PLOS ONE

RESEARCH ARTICLE

An Alaska Native community's views on

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TARGET ARTICLE

Extending Research Protections to Tribal Communities

Bobby Saunkeah^a, Julie A. Beans^b, Michael T. Peercy^c, Vanessa Y. Hiratsuka^b, and Paul Spicer^d

^aChickasaw Nation Department of Health; ^bSouthcentral Foundation; ^cUniversity of Oklahoma

ABSTRACT

The history of research in American Indian/Alaska Native (AI/AN) communities has been marked by unethical practices, resulting in mistrust and reluctance to participate in research. Harms are not limited to individual persons—tribal communities experience harmful misrepresentation and generalizations disrespectful of AI/AN groups' heritage, cultures, and beliefs. The Belmont Report's research ethics principles are applied primarily to protect individual research participants. The principles of sovereignty and solidarity are argued to be important concepts in extending Belmont's research protections to tribal communities. Sovereignty, an expression of respect for autonomy at a group level, is the basis for tribal self-determination. The principle of solidarity provides an ethical underpinning for tribes' obligations to protect community interests and culture. Extension of Belmont through these principles should serve to minimize harms to AI/AN groups in research.

KEYWORDS

Alaska Native; American Indian; Belmont Report; CBPR; solidarity; sovereignty

OPEN ACCESS

Citation: Hiratsuka VY, Beans J, Saunkeah B, Blacketer E, Lund JR, Alaska Native community's view research, testing, and return of from a public deliberation. PLoS ONE 2021; 16(10): e0229540. <https://doi.org/10.1371/journal.pone.0229540>

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INTRODUCTION

As recently as 2010, a dispute was settled where

Scoping Review Findings

- Data points relevant to community-level engagement in and regulation of research, community research capacity and cultural adaptation were extracted from 178 articles.
- Community engagement varied across study components:
 - 76% of the articles reported community participation in research-related meetings and other events
 - 27% of the articles reported community involvement in initiation of research
 - 88% of the articles reported use of community-level tools to guide or regulate research.
 - 52% of the articles reported that community members received research-related training.
- Findings suggest a need for ...
 - increased community engagement in early stages of the research process
 - reporting guidelines for participatory research involving American Indian and Alaska Native communities
 - further existing research on the impact of different components of participatory research on process and outcome measures
 - develop funding mechanisms that account for the time and resource intensive nature of participatory research.



Review

Health-Related Participatory Research in American Indian and Alaska Native Communities: A Scoping Review

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Abstract: A scoping review was conducted to assess the state of the literature on health-related participatory research involving American Indian and Alaska Native communities. Online databases were searched for relevant articles published between 1/1/2000 and 5/31/2017. 10,000+ data points relevant to community-level engagement in and regulation of research, community research capacity and cultural adaptation were extracted from 178 articles. Community engagement varied across study components: 136 (76%) articles reported community participation in research-related meetings and other events and 49 (27%) articles reported community involvement in initiation of research. 156 (88%) articles reported use of community-level tools to guide or regulate research. 93 (52%) articles reported that community members received research-related training. 147 (82%) articles described some type of cultural adaptation. Across all articles, data points on community engagement were not reported in 3061 (40%) out of 7740 cases. Findings suggest a need for increased community engagement in early stages of the research process and for reporting guidelines for participatory research involving American Indian and Alaska Native communities. There is also need to further existing research on the impact of different components of participatory research on process and outcome measures and to develop funding mechanisms that account for the time and resource intensive nature of participatory research.

Keywords: American Indian; Alaska native; community engagement; participatory research; health research; scoping review

1. Introduction

Participatory research (PR) is an umbrella term for a suite of research approaches—including participatory action research, community-based participatory research, and tribal participatory research—that share a broad emphasis on balancing generation of scientific knowledge with interventions that benefit communities, promoting community engagement in and shared control over research processes, developing the capacity of communities to participate actively in research, and adapting research objectives and processes to the needs and expectations of participating communities [1,2]. Participatory action research is characterized by a cycle of reflective inquiry undertaken by communities and researchers to inform action for positive social change, equitable power sharing between researchers and researched groups, and an emphasis on community engagement in all stages of the research process [3]. Community-based participatory research is guided by principles that call for equitable relations and co-learning among researchers and communities;

Newborn Screening- CPT1A Arctic Variant

- Newborn screening in Alaska includes screening for carnitine palmitoyltransferase 1A (*CPT1A*) deficiency
- The *CPT1A* Arctic variant is a variant highly prevalent among Indigenous peoples in the Arctic.
- Focus groups of Alaska Native (AN) community member and AN-serving healthcare providers' knowledge and perspectives on the *CPT1A* Arctic variant were conducted.

- Respect sovereignty
- Respect self-determination- of individuals and communities
- Follow the lead of the community
- Practice transparency
- Practice humility
- Acknowledge harms
- Build local capacity
- Make a long-term commitment
- Be flexible and creative

Questions?

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Center for the Ethics of Indigenous Genomic Research

<https://www.ou.edu/cas/anthropology/ceigr>