

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

Vanessa Hiratsuka, MPH, Jennifer Brown, BA, and Denise Dillard, PhD

Southcentral Foundation

What Is the Purpose of This Study?

- The purpose of this study was to explore the views of biobanking research among Alaska Native community members and leaders across the state of Alaska using a community-based participatory research approach with tribal and federal partners.
- The team undertook a partnership approach to outreach to individual tribes and regional tribal health organizations to partner and guide the study team in the conduct of focus groups in different Alaska Native communities.
- In the process of considering biobanking research, Alaska Native people spoke of contextual factors that informed their opinions on research participation and the storage of biological specimens in research.

What Are the Problems?

- There has been a persistent underrepresentation of minority community members in biomedical research, and specifically in genomic research.
- Although communities and individuals may choose not to participate because of mistrust in research, lower participation also limits the application of project findings to health disparities in their communities.
- To date, there have been no research efforts seeking the viewpoint of Alaska Native people on biobanking, despite a rich history of biobanking research using banked specimens from Alaska Native people.

What Are the Findings?

- Community members described an awareness of past clinical research and surveillance projects, including community-stigmatizing research, which influenced their views on future research participation.
- There is a need to actively address and dialogue with community leaders and members regarding the community memory of research when engaging in research with marginalized communities.

Who Should Care the Most?

- Organizations that want to assess health issues affecting a given community collecting or using biobanked specimens.
- Organizations interested in assessing the health status of people within Alaska Native communities.
- Organizations and researchers interested in improving the health of Alaska Native people.
- Organizations interested in forming community-based participatory research partnerships.

Recommendations for Action

- Increase the role of Alaska Native community members in research.
- Through community and academic partnerships, educate all members of the research team on past clinical research and surveillance projects conducted within the community.