

ETHICAL AND CULTURAL IMPLICATIONS OF SPECIMEN BANKING AMONG ALASKA NATIVE PEOPLE: HISTORICAL PROJECT.

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Background: The use of human biological specimens in research studies has occurred in Alaska since the 1950s. Approximately 532,500 serum specimen aliquots from 91,500 individuals are currently housed at the Arctic Investigations Program of the Centers for Disease Control (AIP CDC) located in Anchorage, Alaska. Specimens from Alaska Native people make up 79% of the bank, 17% of the samples are from non-Native people, and 4% are unknown. The historical project focuses on when and how the AASB was created and how it has been used and governed over time. This includes changes in consent for collection, storage and use. This chronology is important as a historical context for discussions regarding policy and procedures for the AASB.

Purpose: To describe initial findings about the inception, use, management and documentation for collection and storage of the Alaska Area Specimen Bank (AASB) over time. Some members of the Alaska Native community have expressed concern about the use and storage of specimens.

Methods: Medical researchers were interviewed about their knowledge and use of the AASB. They were specifically queried about research approval processes and consent. Archived periodicals were used to cross reference information shared by informants and contemporary documentation.

Results: The AASB was created around 1960, but no informants involved at inception have been interviewed to date. In 1973, management was transferred from the Arctic Health Research Center (a university-based site) to the Arctic Investigation Program at the Centers for Disease Control and Prevention (CDC) in Anchorage, Alaska. Research since 1973 has predominantly involved immunizations or improved screening for a pressing public health issues. Consent processes have become increasingly detailed with more regulations and reviews by Tribal Health Organizations, village councils, and institutional review boards. Management of the AASB is now the joint responsibility of the CDC and a group of Alaska Native leaders from across the state.

Conclusions: Accounts of the early years of the serum bank are less defined than more recent years. Preliminary information gathered does not reveal evidence of inappropriate access or use of the AASB. Future work will focus on obtaining additional information about the early years of AASB.

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