

NIH Tribal Consultation  
June 6, 2017

65,000  
VOICES

# NIH Research Within the Nuka System of Care: *Research with Alaska Native People*

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*Alaska Native People Shaping Health Care*



# Objective

- Provide an example of how Tribal and scientific communities are working together to develop meaningful research projects funded by the National Institutes of Health



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# Research in Alaska

- History of research in Alaska Native communities
  - 1940s Tuberculosis studies
  - 1950s Air Force Aeromedical Laboratory Thyroid Function Study (Radioactive Iodine-131)
  - 1970s Hepatitis studies
  - 1979 Barrow Alcohol Study



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# History



**1982** - Cook Inlet Region Inc. (CIRI) establishes SCF as a 501(c)(3) nonprofit

**1985** - SCF enters into its first self-management contract (dental, optometry, community health) with the government

**1998** - Assumes management of the region's entire primary care system

**1999** - Assumes co-ownership and co-management of services for the Alaska Native Medical Center

**2000** - Introduces relationship-based Nuka System of Care: integrated care teams, same day access to care and much more

**2001** - Formalization of research approval process

**2003** - New Fireweed Building opens to house state-of-the-art dental, optometry and behavior health services

**2004** - SCF Research Department established

**2009** - Anchorage Native Primary Care Center expands with new 80,000-square-foot wing

**Today** - Baldrige award recipient; 1,600 employees; 65+ programs



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# SCF Research Approval

SCF review and approval of research is required ...

- When Alaska Native/American Indian (AN/AI) participants are recruited at any SCF facility or on the Alaska Native Medical Center campus.
- When research conducted will use information from the Alaska Native Medical Center health record.
- When SCF employees are engaged in the research.



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# Research Review Process

- SCF review and approval must occur before any recruitment or data collection begins.
- Review and approval is required prior to any dissemination of findings.
- Review and approval is required for:
  - Research concept
  - Protocol
  - Presentation of preliminary findings
  - Final reports and manuscripts



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# SCF Research Review Criteria

- Alignment with SCF vision, mission, key points, goals, and objectives.
- Appropriate depiction and involvement of AN/AI people.
- Appropriate topic selection and handling.
  - Sensitive topics
- Quality of research design.
- In compliance with SCF Guidelines for Researchers



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# Vision

A Native Community  
that enjoys physical,  
mental, emotional  
and spiritual wellness

# Mission

Working together with  
the Native Community  
to achieve wellness  
through health and  
related services



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# Corporate Objectives

- Reduce the rate of domestic violence, child abuse and neglect.
- Reduce the rate of and improve the management of cancer.
- Reduce the incidence of suicide.
- Reduce the rate of obesity.
- Reduce the rate of substance abuse.
- Reduce the rate of and improve the management of diabetes.
- Improve oral health
- Reduce the rate of and improve the management of cardiovascular disease.



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# Past SCF Research Projects

- Ethical and Cultural Implications of Specimen Banking Among Alaska Native People (2004 - 2008)  
NIH/NHGRI



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# SOUTHCENTRAL FOUNDATION | RESEARCH DEPARTMENT

Southcentral Foundation recognizes the value of research in the medical, social and physical sciences to Alaska Native people and society in general.

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The newsletter content is created by the Research Department. If you have any questions or concerns regarding this newsletter, please contact the Research Department at:

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Centers for Disease Control Arctic Investigations Program Building, location of the Alaska Area Specimen Bank, Anchorage, Alaska

Photo used with permission

## Specimen banking among Alaska Native people: ethical and cultural implications

Specimens like blood and saliva are stored in a specimen bank in Anchorage, Alaska, near the Alaska Native Medical Center. The specimens were gathered by doctors and researchers to learn about health. Specimens have been stored since the 1960s and continue to be collected today. Most specimens are from Alaska Native people. The specimen bank is run by the Centers for Disease Control in partnership with a working group that includes tribal leaders from across Alaska.

Southcentral Foundation has done a study about the specimen bank. We learned about the history of the bank, what is in the bank and what some Alaska Native people think about research and storage of specimens.

We will share what we learned in this newsletter. We will also share information about the specimen bank today.

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## A brief history of the specimen bank

By SCF Research Department

Certain health problems have had a big effect on Alaska Native people. For example, a lung disease called tuberculosis used to kill many Alaska Native people. Many babies and children passed away very young due to this disease and doctors often weren't sure why.

Specimens were collected by doctors and researchers to learn more about these health problems. Doctors began to save these specimens in case new things were learned to help those who were sick.

The United States government then gave funding to Alaska in 1948 to start a health research center in Alaska. The center has changed names and locations several times. It

was originally in Anchorage then moved to Fairbanks. It is now located in Anchorage once again.

The United States government used to make most of the decisions about storage and use of specimens. Alaska Native tribal health organizations have now taken charge of their health care.

Alaska Native health leaders now partner with the federal government to manage the bank.

Researchers who want to store specimens or use specimens must have tribal approval.

Research using specimens in the bank today mostly focus on the following:

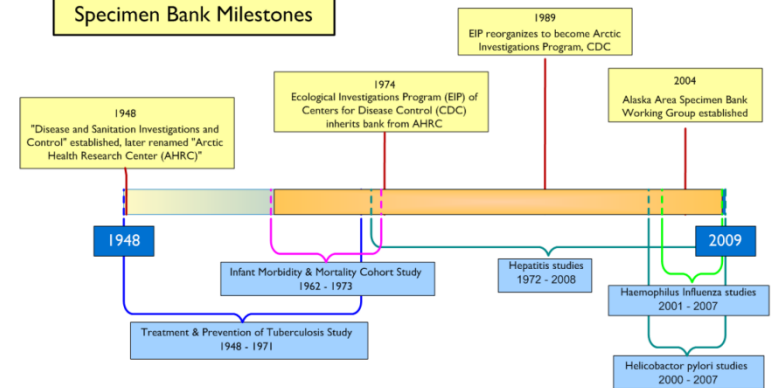
- Hepatitis, which is a liver disease
- Haemophilus influenza, a cause of meningitis in children.
- Helicobacter pylori, a cause of stomach cancer.

These specimens have led to vaccines to prevent hepatitis among Alaska Native people and other populations throughout the world.



Public Health Safety employees in Alaska in 1960  
Photo used with permission.

### Specimen Bank Milestones



### Examples of Research Studies Using the Specimen Bank



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## What is stored in the specimen bank

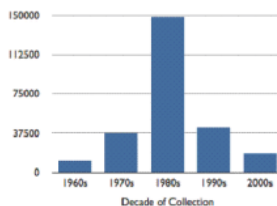
The specimen bank has specimens from 87,763 people across Alaska. 93 percent of the specimens are blood, which are stored in small tubes and kept frozen. Other specimens include tissue and other fluids from the body.

Here is a breakdown of the specimens collected:

- 91 percent are from Alaska Native people
- 55 percent are from women
- 61 percent are from adults 18 to 59 years
- 82 percent are from people still alive

### WHEN WERE SPECIMENS COLLECTED?

Specimens were collected as far back as the 1960's. However, 58 percent of the specimens were collected in the 1980s.



Many specimens in the bank are still being used to learn about health.

### MOST SPECIMENS WERE COLLECTED TO LEARN ABOUT INFECTIOUS DISEASES

94 percent of the specimens were collected to learn about infectious diseases.

Infectious diseases like tuberculosis can be spread from one person to another.

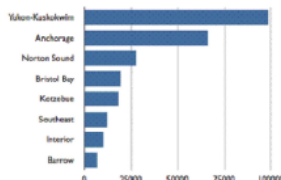
Specimens have also been used to learn about cancer,

health concerns in pregnant women and injuries.

Some have been used to study the how the environment affects health.

### WHERE ARE THE SPECIMENS FROM?

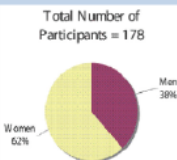
Although specimens were collected throughout Alaska, 58 percent are from the Yukon-Kuskokwim region.



## What do Alaska Native people think about specimen collection

We talked to people in 14 communities across Alaska in gatherings called focus groups. We had focus groups with younger people, older people and Tribal leaders.

In each focus group, we asked



questions such as:

"What do you think about researchers collecting specimens from you for studies?"

We also asked more specific questions like:

"What should happen to a specimen in the bank if the person who gave it passes away?"

We then looked at what people said for patterns or important ideas mentioned more than once.

### WHAT DO YOU THINK ABOUT RESEARCHERS COLLECTING SPECIMENS?

People brought up many ideas when explaining what they thought. Some talked about past research or medical care in their community or family. Some felt mistreated by researchers, doctors, or others from the United States government.

Others mentioned their Alaska Native culture and that specimens were very special and not just blood.

*Continued on page 4, "View"*

## Your views on specimens, continued from page 3

There were concerns about the research that could be done in the future with new technology.

Some were also concerned about research that singled out Alaska Native people.

People also said many things about how this kind of research may help Alaska Native people and their health. It could help now and in the future even if it didn't help them personally.

### WHAT WOULD YOU WANT TO KNOW WHEN DECIDING WHETHER TO JOIN A STUDY?

People said they would want to know many things when thinking about joining a research study using specimens.

- Many said they'd want to know more about the

research when deciding whether to join.

- Most said they wanted to know what the results were when the study was done.
- Many people had questions about the specimens and how they're stored in the bank.
- People were curious about how long a specimen is good for and how the bank keeps them safe.

### WHO SHOULD GIVE PERMISSION?

We also asked questions about what should happen with specimens already in the specimen bank when permission isn't clear. This would include when someone who gave the specimen passes

away.

Some people thought the specimens should be destroyed and others thought the specimen bank should keep them.

More than a few people thought a family member or other chosen person should decide.

We also asked how tribal health organizations should be involved in giving permission to researchers.

Some people said each individual should make the decisions.

Others thought tribal health organizations should help decide what research should be done in the region.

We will share this information with tribal leaders who may use it to make future decisions about research.

## The specimen bank today: environment and security

By SCF Research Department

Specimens are stored today in specially designed freezers as cold as -112 degrees Fahrenheit. They are usually stored in test tubes.

Test tubes do not have the name or other information which could identify the person who gave the specimen.

The specimen bank building and freezers are locked at all times and only specimen bank staff can enter.

Researchers who want to store

or use specimens in the bank go through many steps to get permission. Permission includes approval by tribal leaders and typically the person who gave the specimen.



A CDC employee showing specimens in the Alaska Specimen Bank.

*Photo courtesy of Center for Disease Control and Prevention*

We'd like to thank everyone who participated in our focus groups and interviews. This project would not have been possible without the support of our community consultants and the hospitality of the communities we visited.

The project was funded by the Native American Research Centers for Health (NOT GM-05-104 Dillard, PI) from the Indian Health Service with support from the National Human Genome Research Institute.



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# Past SCF Research Projects

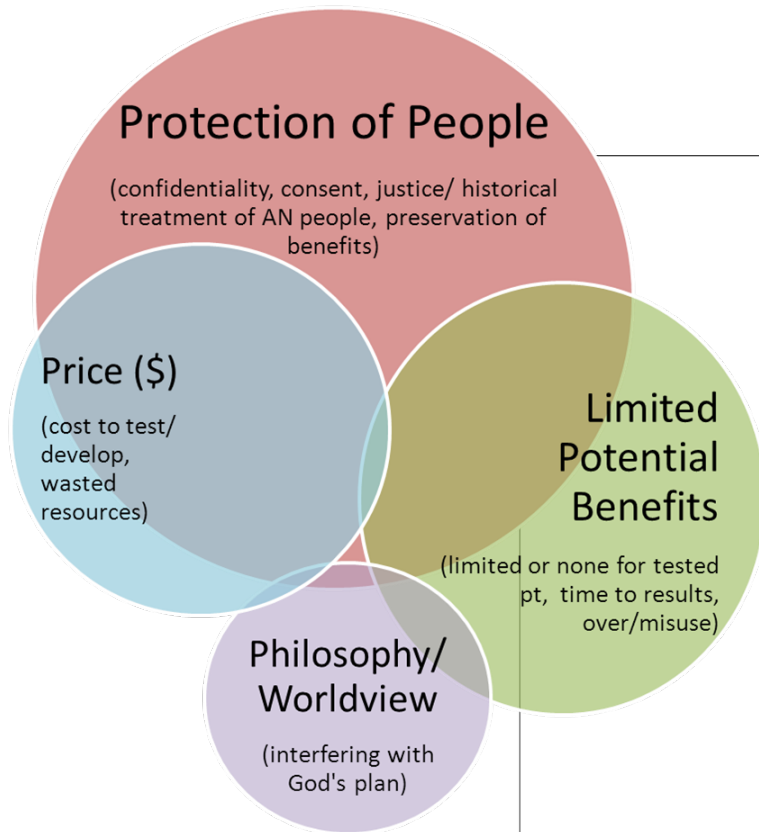
- Pharmacogenetics Among Alaska Native People (2010 – 2015) NIH/NIGMS
  - Ethical considerations
  - Warfarin
  - Tamoxifen



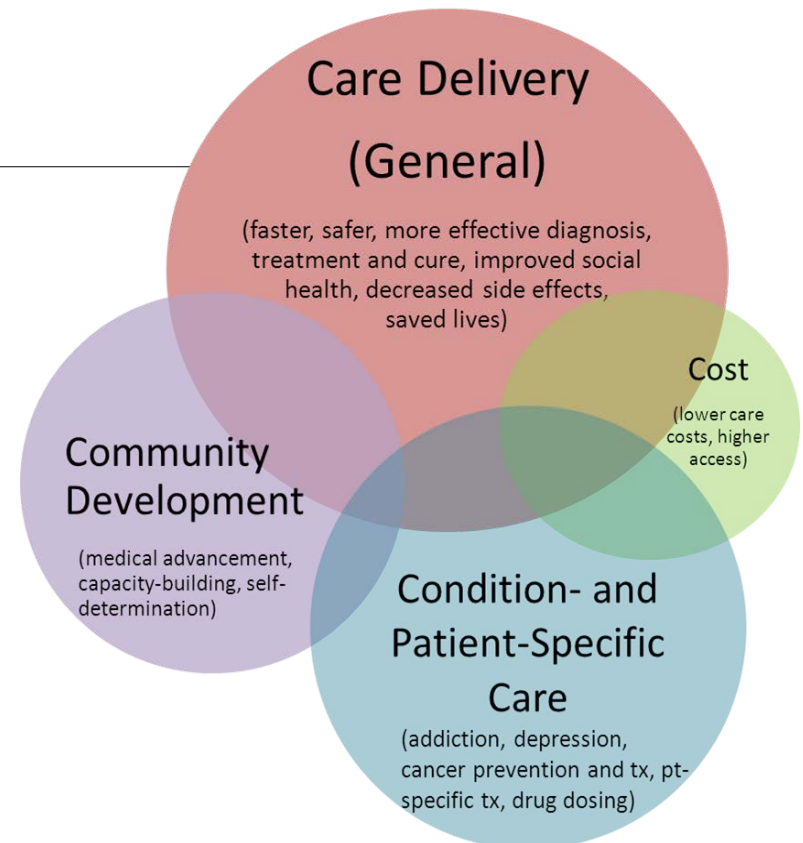
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# Risks



# Rewards



Risks, Rewards and the Double-Edged Sword: Pharmacogenetic Testing and Research in the Alaska Native/American Indian Community



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## Double-Edged Sword

PGX/PGR only with  
protections for :

- Voluntariness
- Confidentiality
- Appropriate consent
  - Oversight
  - Individual and community benefits
- Stigma/stereotypes



PGX/PGR preferred if:

- Reduces cost/expands access
  - Improves tx efficacy/timeliness
- Improves health of AN people
- Improves health of all people

Risks, Rewards and the Double-Edged Sword: Pharmacogenetic Testing and Research in the Alaska Native/American Indian Community



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# Current SCF Research Projects

- Southcentral Foundation Research Center for Alaska Native Health (2013 – 2018)
  - Capacity building (NIH/NIGMS)
  - Tobacco pharmacogenetics (NIH/NIDA)
  - Explanatory models of alcohol misuse (NIH/NIAAA)



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# Questions?



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# Thank You!

**Qaġaasakung**  
*Aleut*

**Quyanaq**  
*Inupiaq*

**‘Awa'ahdah**  
*Eyak*

**Mahsi'**  
*Gwich'in Athabascan*

**Igamsiqanaghalek**  
*Siberian Yupik*

**Háw'aa**  
*Haida*

**Quyana**  
*Yup'ik*

**T'oyaxsm**  
*Tsimshian*

**Gunalchéesh**  
*Tlingit*

**Tsin'aen**  
*Ahtna Athabascan*

**Quyanaa**  
*Alutiiq*

**Chin'an**  
*Dena'ina Athabascan*



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# SAVE THE DATE!

**Southcentral Foundation**  
**2015 Nuka System of Care**  
**Conference**  
**June 15-19, 2015**

**For more information, contact:**

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