Research in Indigenous Communities

Suicide Prevention in Indigenous Communities: A Virtual Workshop

National Academies of Sciences, Engineering, and Medicine

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65,000 Voices

Southcentral
Foundation

Objectives

- Summarize what Alaska Native and American Indian community members and leaders have shared about how to conduct research
- Describe how Southcentral Foundation expresses sovereignty over research and data
- Share a case example of suicide prevention research

Background

- Biological samples have been used for research and stored in the Alaska Area Specimen Bank for over 70 years
- In 2004, Alaska Native Tribal Health Organizations assumed shared ownership and management of the Bank with the Centers for Disease Control and Prevention.
- Alaska Native leaders asked for research to explore how community members viewed research using stored biological samples.

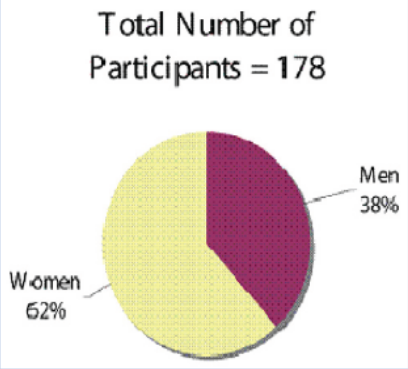
Hiratsuka, V., Brown, J., Lockhart, A., & *Dillard, D*. (2012). Views of biobanking research among Alaska Native people: The role of community context. Progress in Community Health Partnerships: Research, Education, and Action, 6(2), 131-9.

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

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"

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.

Recommendations for Researchers

- Gain awareness of past research projects.
- Work with the community to determine how to treat collected data and specimens with respect.
- Provide clear, jargon free information in the informed consent including a data and specimen destruction date.

Recommendations for Researchers

- Give participants options through tiered consent.
- Share information on progress throughout the research.
- Return results to participants and the community.
- Have community leaders review and approve study findings prior to publication and presentation.

Perspectives on Pharmacogenetic Research and Clinical Testing Among Alaska Native People

- Four focus groups (total N=32) with Alaska Native community members
- Views elicited about pharmacogenetic research. Pharmacogenetics is the use of genetic information to guide selection of medications.

Shaw, J. L., Robinson, R., Starks, H., Burke, W., & *Dillard, D. A.* (2013). Risk, reward and the double-edged sword: Perspectives on pharmacogenetic research and clinical testing among Alaska Native people. American Journal of Public Health, 103(12), 2220-5. PMCID: PMC3828986.

Results

Risks

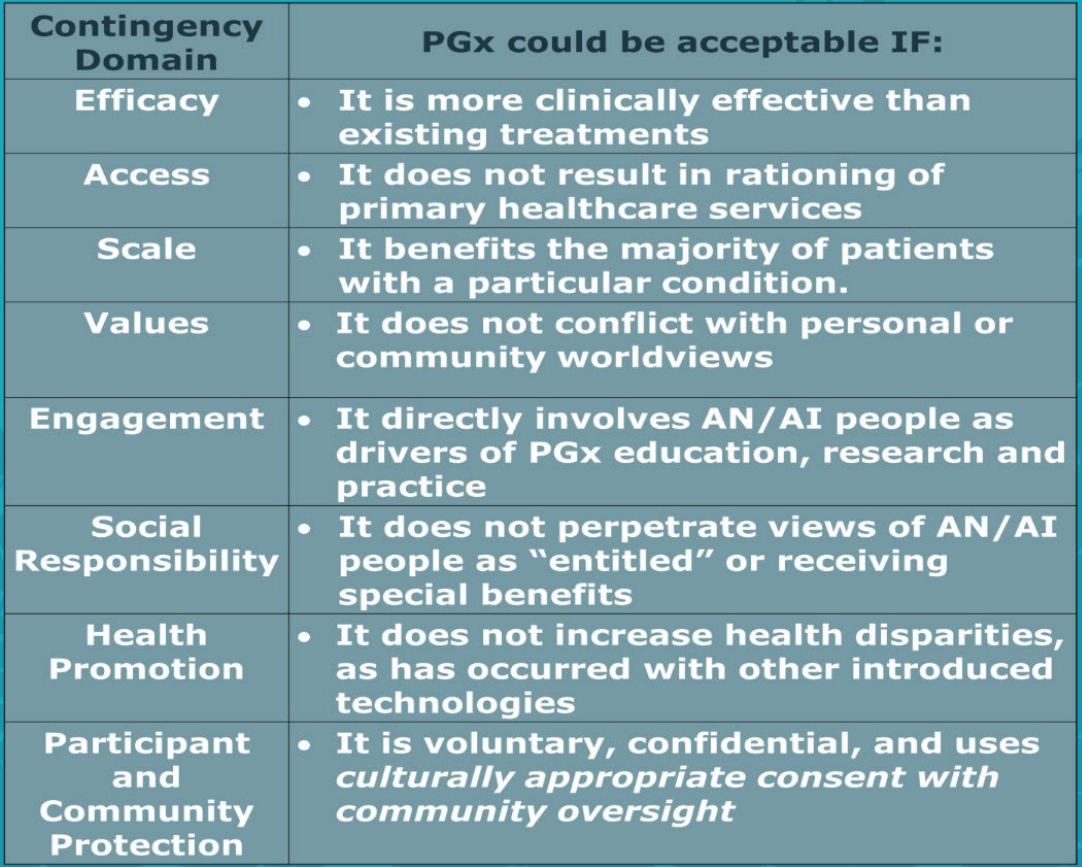
- Lack of adequate protections
- Increased cost/ decreased access
- Limited utility

Rewards

- Community development/ capacity building
- Decreased costs/ increased access
- Improved health/decreased side effects

- Pharmacogenetics **generally endorsed** for potential rewards of improved health and healthcare as well as capacity building
- But, pharmacogenetics also viewed as a “double-edged sword” with **potential to harm *and* heal** in Alaska Native communities.
- Community members described **conditions** to ensure that rewards outweighed potential risks.

8 Contingencies



Contingency Domain	PGx could be acceptable IF:
Efficacy	• It is more clinically effective than existing treatments
Access	• It does not result in rationing of primary healthcare services
Scale	• It benefits the majority of patients with a particular condition.
Values	• It does not conflict with personal or community worldviews
Engagement	• It directly involves AN/AI people as drivers of PGx education, research and practice
Social Responsibility	• It does not perpetrate views of AN/AI people as "entitled" or receiving special benefits
Health Promotion	• It does not increase health disparities, as has occurred with other introduced technologies
Participant and Community Protection	• It is voluntary, confidential, and uses *culturally appropriate consent with community oversight*

Exploring Pathways to Trust

- Tribal leaders shared perspectives on data sharing at meeting with researchers and funders.
- Strong support for efficient research which translates knowledge to benefit
- BUT… benefits of research often poorly defined, indirect & long-term versus immediate potential harms like stigma
- Data sharing policies fall under a trust relationship with the federal government requiring meaningful tribal consultation

James, R., Tsosie, R., Sahota, P., Parker, M., *Dillard, D,* Sylvester, I., Lewis, J., Klejka, J., Muzquiz, L., Olsen, P., Whitener, R., Burke, W. (2014). Exploring pathways to trust: A tribal perspective on data sharing. Genetics in Medicine, 16(11), 820-6. PMCID: PMC4224626.

SCF Governance of Research

- Approval by SCF Board of Directors (100% Alaska Native)
- Approval of the general idea before applying for funding
- Approval of the detailed plan for research
- Receipt of signed Research Agreement is required before any data collection begins
  - Specifies ownership and return of data and specimens, required review and approval, Native hire preference
- Approval required before any findings are released

Hiratsuka, V.Y., Beans, J.A., Robinson, R. F., Shaw, J.L., Sylvester, I., & Dillard, D.A. (2017). Self-determination in health research: An Alaska Native example of tribal ownership and research regulation. International Journal of Environmental Research and Public Health, 14(11), pii: E1324. doi: 10.3390/ijerph14111324. PMCID: PMC5707963.

Predictive Algorithm to Identify Risk of Suicide in a Tribal Health System (PAIRS)

ALASKA INBRE
IDeA Network of Biomedical Research Excellence

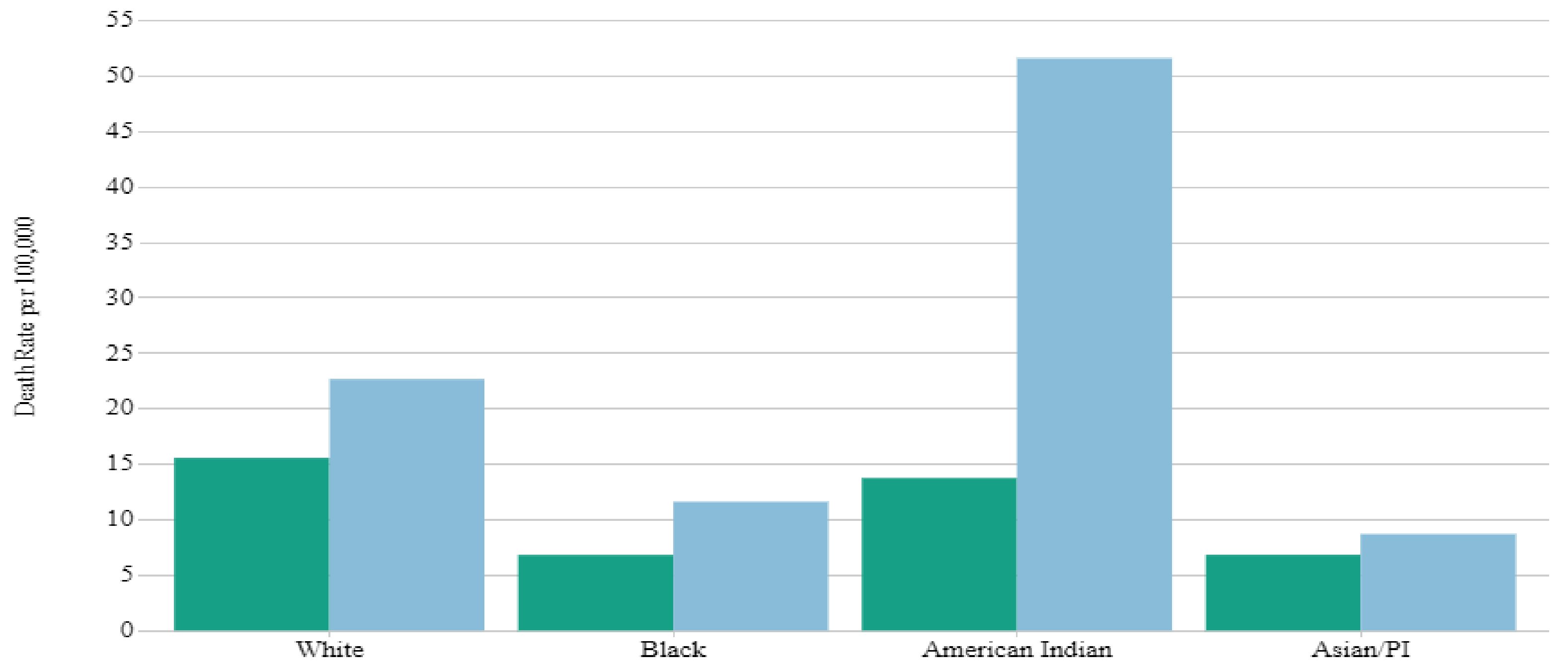
Southcentral Foundation

MHRN Mental Health Research Network

Funded by National Institute of General Medical Sciences of the National Institutes of Health under grant number P20GM103395.
The content is solely the responsibility of the authors and does not necessarily reflect the official views of the NIH.

Background

Suicide in Alaska and the U.S. by racial category for 2016-2020.



Centers for Disease Control and Prevention. National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS). Accessed June 9, 2022. Available from URL: www.cdc.gov/injury/wisqars

Background

- Health systems are important sites for suicide prevention.
- Self-report screening tools, such as PHQ-9, are important but limited for detecting suicide risk.
- Predictive analytic approaches hold promise for improving clinical suicide prevention efforts.

Predicting Suicide Attempts and Suicide Deaths Following Outpatient Visits Using Electronic Health Records

Gregory E. Simon, M.D., M.P.H., Eric Johnson, M.S., Jean M. Lawrence, Sc.D., Rebecca C. Rossom, M.D., M.S., Brian Ahmedani, Ph.D., Frances L. Lynch, Ph.D., Arne Beck, Ph.D., Beth Waitzfelder, Ph.D., Rebecca Ziebell, Robert B. Penfold, Ph.D., Susan M. Shortreed, Ph.D.

Study 1 Aim & Methods

- In 2018, we partnered with the Mental Health Research Network to evaluate the accuracy of an EHR-based algorithm for predicting suicide risk among AN/AI people in primary care.
- Originally developed in a general population sample, using EPIC EHR data, to predict risk of suicide attempt for up to 90 days after a general healthcare visit among people ages 13 and older with a behavioral health diagnosis.
- Model applied to SCF Cerner EHR data for primary care visits from Oct 2016-Mar 2018 and evaluated using logistic regression.

Past 5 Years	Past 1 Year	Past 3 Months
suicide attempt	suicide attempt	suicide attempt
depression dx	injury/poisoning dx	benzodiazepine Rx
anxiety dx	ER visit for behavioral health	
substance use disorder dx	hospitalization for behavioral health	
personality disorder dx		
schizophrenia dx		
eating disorder dx		
PTSD dx		

Example variables

Study 1 Results

Risk Percentile	Actual Attempts ÷ Predicted Attempts	Actual Attempts ÷ Total Attempts
>99.5th	25.7%	10.4%
99th to 99.5th	16.0%	6.5%
95th to 99th	7.2%	23.1%
90th to 95th	2.7%	10.9%
75th to 90th	1.9%	22.6%
50th to 75th	0.8%	16.6%
<50th	0.3%	10.0%

- 47,413 qualifying primary care visits made by 10,864 patients.
- 589 visits (1.2%) were followed by a suicide attempt within 90 days.
- Visits stratified in the top 5% of risk accounted for 40% of actual attempts.
- Among visits in the top 0.5% of predicted risk, 25% were followed by actual suicide attempt.
- The best fitting model had an AUC of 0.826 (95% CI: 0.809-0.843).

ORIGINAL ARTICLE

Suicide and Life-Threatening BEHAVIOR

Validating a predictive algorithm for suicide risk with Alaska Native populations

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Julia J. Smith MS[1] | Mike Mosley BA[1] | Kate M. Lillie PhD[1] |
Jaedon P. Avey PhD[1] | Rebecca Ziebell BS[3] | Gregory Simon MD, MPH[3]

Suicide & Life-Threatening Behavior, March 2022, DOI:10.1111.sltb.12853

Study 2 Aim

Engage tribal health system stakeholders to identify implementation strategies for a validated suicide risk algorithm that are culturally acceptable, clinically effective, and operationally feasible.

Study 2 Methods

Developed 3 implementation scenarios to elicit stakeholder feedback:

- Informed by Kaiser Perm Washington, Health Partners, and VA
- Adapted to align with SCF organizational culture.
- Emphasized key aspects of implementation, including outreach strategy, workload, and communication.

SCENARIO 1

Active: patient outreach by nurse case manager

SCENARIO 2

Passive: primary care visit-based outreach

SCENARIO 3

Active: patient outreach by intensive case manager

Study 2 Methods

Semi-structured interviews with SCF patients, providers, and leaders.

Topic	Sample Questions
Using personal data to predict health risk in general	What do you think about using health record data to predict health risk (e.g., heart disease, diabetes)?
Using personal data to predict suicide risk	What do you think about using health record data to predict risk of suicide attempts at SCF?
Implementation approaches	What are your initial thoughts about the scenario? What did you like? What didn't you like? What could be changed to make the experience better for the customer-owner?
Ethics	What concerns or questions do you have about this scenario?
Fit	Are there specific aspects of each scenario that are particularly well or ill-suited for implementation at SCF?

Study 2 Results

- N=30 (15 patients; 15 providers/leaders)
- Most patients were female (93%), aged 25-54 (73%), and spent most of their lives in rural communities (60%).
- 40% reported a personal history of suicidal ideation or attempt and 93% reported having provided direct support to someone experiencing suicidal ideation or attempt.
- 93% of providers/leaders had suicide prevention training and provided clinical care related to suicide prevention.

Study 2 Results: Patients

- Patient participants universally endorsed using risk algorithms to prevent suicide n the helath system—with key caveats.
  - Health system must be transparent with the community about this use of medical records.
  - Privacy of risk information is paramount, i.e. only providers should have access to action lists to protect against breech of confidentiality and stigma.
  - Should be done in primary care by trained professionals to avoid “false positives”/stigma.
  - Should be done in person (not remotely), both in clinic and in community settings.
  - Should be done by behavioral health staff and/or provider with relationship to the patient.
  - Intentional communication is key—non-judgmental, personalized, non-routinized.
  - Intervening staff should have knowledge of resources (e.g., ICM vs NCM) for referral to needed health and social services (e.g., counseling, groups, housing).

> *“I feel like it’s honestly a great idea, because I feel like that will show that you know, a person really does need help and might actually need help in that moment… I feel like that would actually benefit a lot of people. Them and their families and their close friends and loved ones.”*

Study 2 Results: Providers/Leaders

- Preferred implementation in primary care (vs. specialty behavioral health care) to ensure coordination of whole-person care.
- Perceived SCF as ideally positioned to successfully implement this approach to suicide prevention.
- Concerns centered around managing increased workloads and access to specialty behavioral health services for increased referrals.

> *"I think that we have a very unique opportunity, with the data set that we have as a relatively closed system that stays with people longitudinally over time, to be able to understand wellness and evaluate risk . . . it's not unlike the wellness care planning and being able to utilize touches in our current system to identify folks who might need a greater intervention."*

> *"Someone has to be kind of the captain of the ship, and that really falls more towards primary care. Because they're gonna be tasked with potentially following this person for their medical, for their psychiatric issues, along with [an integrated behavioral health consultant]."*

Conclusions

- These studies validated and found broad support in a large Tribal health system for an approach to suicide prevention that uses routinely-collected medical record data.
  - Among health system stakeholders, perceived benefits outweighed perceived risks of this approach.
- Implementation strategies should:
  - Include intentional, well-planned strategies for communication with individuals and the community about the use, intent, and application of this approach to suicide prevention.
  - Account for increased workload, referrals and care coordination needs among staff tasked with outreach, assessment, intervention and/or referral.
  - Balance safety concerns with privacy concerns to ensure timely intervention AND sustain patients' trust in the health system.

Thank You!

Qaĝaasakung
Aleut

Quyanaa
Alutiiq

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

Chin'an
Dena'ina Athabascan

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