Southcentral Foundation
Research Update

NCAI Mid Year Conference, June 20-24, 2021

Denise A. Dillard, Director of Research
Objectives

- Describe how Southcentral Foundation (SCF) has expressed tribal sovereignty over research and built its research capacity
- Provide a few examples of studies within the SCF research portfolio
Introduction
History

1971 – Alaska Native Claims Settlement Act

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

Today - Baldrige award recipient 2011 & 2017; 65,000 customer-owners; 1,600 employees (more than 50% Alaska Native or American Indian); 65+ programs
Southcentral Foundation

- Anchorage
- Matanuska-Susitna Borough
- 55 rural villages
- 107,400 square miles
SCF Governance of Research

- Research policy developed in 2005
  - Requires approval of research with SCF customer-owners, within SCF facilities, and/or involving SCF employees
  - Initial review by research committee with researchers, providers, medical and other directors (previously Vice Presidents)
  - Approval by SCF Board of Directors (100% Alaska Native)

Review and approval is required for:

• A research concept before a funding application is submitted or full protocol is developed
• All protocols before any recruitment or data collection begins
• Presentations, final reports, and manuscript prior to any dissemination
• Final reports and manuscripts
SCF Research Review Criteria

- Alignment with SCF vision, mission, key points, goals, operational principles, and corporate objectives
- Potential benefits and harms
- 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 and terms of SCF Research Agreement
Operational Principles

- Relationships between customer-owner, family and provider must be fostered and supported.
- Emphasis on wellness of the whole person, family and community (physical, mental, emotional and spiritual wellness).
- Locations convenient for customer-owners with minimal stops to get all their needs addressed.
- Access optimized and waiting times limited.
- Together with the customer-owner as an active partner.
- Intentional whole-system design to maximize coordination and minimize duplication.
- Outcome and process measures continuously evaluated and improved.
- Not complicated but simple and easy to use.
- Services financially sustainable and viable.
- Hub of the system is the family.
- Interests of customer-owners drive the system to determine what we do and how we do it.
- Population-Based systems and services.
- Services and systems build on the strengths of Alaska Native cultures.
Established in 2006
- Within Executive and Tribal Services Division, one of 6 existing SCF divisions

Guided by three factors:
- Health priorities and interests of the customer-owner population
- Guidance and direction from the board of directors and senior organizational leadership
- Funding opportunities
Family Wellness

Corporate Goal

FAMILY WELLNESS
We value the family as the heart of the Native Community. We work to promote wellness that goes beyond absence of illness and prevention of disease. We encourage physical, mental, social, spiritual and economic wellness in the individual, the family, the community and the world in which we live.

Corporate Objectives

FMW1
Reduce the rate of domestic violence, child abuse and neglect.

FMW2
Reduce the rate of and improve the management of cancer.

FMW3
Reduce the incidence of suicide.

FMW4
Reduce the rate of obesity.

FMW5
Reduce the rate of substance abuse.

FMW6
Reduce the rate of and improve the management of diabetes.

FMW7
Improve oral health.

FMW8
Reduce the rate of and improve the management of cardiovascular disease.

FMW9
Improve customer-owner overall health.
<table>
<thead>
<tr>
<th></th>
<th>2006</th>
<th>2014</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prime</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NIH</td>
<td>1 research project, 2 demonstration projects</td>
<td>2 research projects, 3 capacity building</td>
<td>2 capacity building, 1 research project</td>
</tr>
<tr>
<td>Other</td>
<td>2 research projects, 3 cores</td>
<td>1 capacity building</td>
<td></td>
</tr>
<tr>
<td><strong>Subcontracts</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tribal partner</td>
<td>1 for technical assistance, 2 research projects</td>
<td>1 for 2 research projects</td>
<td>1 research project, 1 capacity building</td>
</tr>
<tr>
<td>University</td>
<td>1 research project</td>
<td>3 universities for 3 research projects</td>
<td>10 universities for 14 research projects, 4 capacity building</td>
</tr>
<tr>
<td><strong>Internal resources</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indirect support</td>
<td>Grants management, finance, contracts, human resources, information technology</td>
<td>Added training and workforce development, improvement</td>
<td>Added public relations</td>
</tr>
<tr>
<td>Direct support</td>
<td>Administrative support and tribal research review, scientific capacity building (30%)</td>
<td>Administrative support and tribal research review, scientific capacity building, internal projects (25%)</td>
<td>Administrative support and tribal research review, scientific capacity building, internal projects, national advocacy (35%)</td>
</tr>
<tr>
<td>Staffing</td>
<td>2006</td>
<td>2014</td>
<td>2021</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>--------------------</td>
<td>------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td><strong>Leadership</strong></td>
<td>Director, manager</td>
<td>Director, manager</td>
<td>Director, manager, supervisor</td>
</tr>
<tr>
<td><strong>Principal investigators</strong></td>
<td>1 senior researcher</td>
<td>2 senior researchers</td>
<td>3 senior researchers</td>
</tr>
<tr>
<td><strong>Other scientific staff</strong></td>
<td>4 researchers</td>
<td>4 researchers, 1</td>
<td>10 researchers</td>
</tr>
<tr>
<td><strong>Other Research Department staff</strong></td>
<td>3 administrative staff</td>
<td>3 administrative staff, 1 intern</td>
<td>3 administrative staff, 6 recruiters, interns</td>
</tr>
<tr>
<td><strong>Other staff in corporation</strong></td>
<td>Physician</td>
<td>Certified medical assistant, behavioral health consultant, data/program analysts, evaluator</td>
<td>Certified medical assistant, substance abuse counselors, data/program analysts, evaluators, physician, medical and other directors</td>
</tr>
</tbody>
</table>
Northwest-Alaska Pharmacogenomics Research Network (NWA-PGRN)

U01GM092676 Thummel & Burke (PIs)
NIGMS
2010-2015

- University of Washington
- University of Montana
- University of Alaska Fairbanks/ Center for Alaska Native Health
- Confederated Salish and Kootenai Tribes
- Yukon-Kuskokwim Health Corporation
- Southcentral Foundation
Four focus groups (total N=32) with Alaska Native community members

Views elicited about pharmacogenetic research in general and for treatment of cardiovascular disease, breast cancer, depression and nicotine addiction
Pharmacogenetics *generally endorsed* for potential rewards of improved individual health, health system sustainability, and community capacity building, but…

Pharmacogenetics also viewed as a “double-edged sword” with potential to *harm and heal* in Alaska Native communities.

Clinical utility and social acceptability of pharmacogenetics *requires variety of conditions be met* to ensure that potential rewards outweigh potential risks.
AN/AI customer-owners on long-term warfarin therapy

Buccal swab and medical record review for demographics, warfarin dose, comorbidities, medications

Targeted genotyping for variants in the VKORC1, GGCX, CYP2C9, CYP4F2 and CYP4F11 genes

Association between therapeutic dose and genetic variation

- Tiered consent - medical record review, storage in Alaska Area Specimen Bank with agreement to recontact for future use
- Consent identified specific genes
- No identifiers sent to UW or other laboratories
- Alaska Native students processed specimens at UW
- Specimens at UW returned or destroyed
- Self-reported heritage and classification into regions
- Agreement to terms of the SCF Research Agreement in terms of tribal review and approval, ownership
Heritage and Stable Warfarin Dose

Hypothesis: Difference in VKORC1 genotype frequencies in these heritage groups is driving the observed difference in stable warfarin dose.
VKORC1-1639 and Stable Warfarin Dose

- Heritage is no longer significant after controlling for VKORC1-1639 genotype
- 34% of dose variability explained by VKORC1 genotype

Trend with Stable Warfarin Dose (Significance)

<table>
<thead>
<tr>
<th></th>
<th>Multivariate</th>
<th>Univivariate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable Warfarin Dose</td>
<td>-1.7 mg/day</td>
<td>-2.1 mg/day</td>
</tr>
<tr>
<td>(p = 1.4e-05)</td>
<td>(p = 1.3e-06)</td>
<td></td>
</tr>
</tbody>
</table>

-1.7 mg/day (p = 1.4e-05)
-2.1 mg/day (p = 1.3e-06)
Blood Pressure: Improving Control Among Alaska Native People

- Funded by National Institute for Minority Health and Health Disparities
  - Prime Washington State University, subaward to SCF
- Intervention: Home blood pressure management (HBPM) devices & additional communication
- Specific Aims
  1. Individual Level: Evaluate interventions impact on BP and secondary outcomes from baseline to 12 months
  2. Provider Level: Evaluate impact on prescribing behaviors in response to participant-initiated reports or communication regarding uncontrolled BP
  3. System Level: Evaluate overall impact on BP control among all customer-owners with hypertension regardless of study arm.
Building tribal research capacity takes time and requires both external and internal resources

- Fiscal support
- Grant administration and other administrative support
- Human resources including individuals who can serve as principal investigators
- Support and time of leadership
- Persistence and advocacy

Expressing sovereignty over research has many potential benefits

- Preventing harmful research
- Maximizing immediate and future potential benefits of research in tribally-identified priority areas
- Offering career and development opportunities to tribal members
Denise A. Dillard
dadillard@southcentralfoundation.com

www.southcentralfoundation.com/services/research
Questions?
Thank You!

Qaqaasakung  Aleut
Mahsi'  Gwich’in Athabascan
Quyana  Yup’ik
Tsin’aen  Ahtna Athabascan

Quyanaa  Alutiiq
Igamsiqanaghalek  Siberian Yupik
T’oyaxsm  Tsimshian

Quyanaq  Inupiaq
Gunalchéesh  Tlingit
Chin’an  Dena’ina Athabascan

AwA’ahdah  Eyak
Háw’aa  Haida
Quyanaa  Yup’ik
Alutiiq  Siberian Yupik
Tsimshian  Tlingit
Dena’ina Athabascan  Dena’ina Athabascan