CHALLENGES IN ENGAGING AND DISSEMINATING HEALTH RESEARCH RESULTS AMONG ALASKA NATIVE AND AMERICAN INDIAN PEOPLE IN SOUTHCENTRAL ALASKA

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Abstract: Alaska Native and American Indian (AN/AI) people have negative research experiences, including lack of timely, respectful, and relevant communication about research findings. Southcentral Foundation (SCF), a tribally owned and operated health care organization in Alaska, has redesigned the health care system, enacted research policies, and established a research department which uses best practices of Community Engaged Research with AN/AI people. Department staff and community members, however, perceive significant limitations in the reach of and satisfaction with ongoing engagement and dissemination efforts. Background information is delineated which supports new approaches in research engagement using SCF as an example.

In this article of the special issue, we describe the background information shared with attendees of the Alaska Native Health Research Forum (Forum) to position activities within the local context. We briefly present the history of health care with Alaska Native and American Indian (AN/AI) people in Alaska and the current Southcentral Foundation (SCF) system of care. We then describe the history of research and the SCF Research Department's current approach. Best practices within Community Engaged Research (CER) with AN/AI are delineated, and we end by comparing our experience with that of other researchers and outlining ongoing engagement and dissemination challenges.

History of Health Care

AN/AI people have historically had negative experiences with health care. The Indian Health Service (IHS), an agency in the federal Department of Health and Human Services, is responsible for providing comprehensive health services for approximately 1.8 million of the nation's estimated 3.3 million AN/AI people (U.S. Census Bureau, 2008). Prior to 1982, health care in southcentral Alaska was operated by IHS. Access to health care was poor, with wait times of weeks to months before the next available primary care appointment (Gottlieb, Sylvester, & Eby, 2008) Care was impersonal and reactive, and there were four to eight hour wait times in urgent care or the emergency department (Driscoll et al., 2013; Gottlieb, 2013). Care was also disjointed and inconsistent, as it was common for patients to see different providers at each visit (Gottlieb, 2013).

Southcentral Foundation's Nuka System of Care

SCF was incorporated under Alaska State Law in 1982, under the tribal authority of Cook Inlet Region Incorporated, a corporation established under the Alaska Native Claims Settlement Act of 1971, and defined as a tribe per the Indian Self Determination and Education Assistance Act of 1975 (Public Law 93-638). SCF is the non-profit organization designated and authorized by Cook Inlet Region Incorporated to administer health programs and activities to AN/AI people residing in the southcentral region, which includes Anchorage, the Matanuska-Susitna Borough, and more than 60 rural villages. In 1985, SCF entered into its first self-management compact under Public Law 93-638 with the federal government to provide dental and optometry services throughout the southcentral region. By 1999, SCF had assumed ownership and management of primary care services for the southcentral region and assumed co-ownership and co-management of the Alaska Native Medical Center (ANMC), a 150-bed hospital in Anchorage, with the Alaska Native Tribal Health Consortium. After consulting at length with the AN/AI community through listening posts, focus groups, and in depth interviews, the SCF health care delivery system was redesigned and aligned with a mission, vision, key points (Table 1), and operational principles (Table 2), with the acronym "RELATIONSHIPS" derived from the community consultation process. Detailed descriptions of the SCF Nuka System of Care are available (Gottlieb, 2013; Gottlieb & Tierney, 2015) with key changes briefly described below.

To reflect shared responsibility, Alaska Native ownership, and respect for individual dignity, SCF immediately changed references from *patients* to *customer-owners*. AN/AI people became *customers* of their health care system, which they tribally *owned*. All customer-owners who received SCF services chose a primary care provider with whom they could build a relationship, and families were encouraged to select the same provider in a patient-centered medical home model (Driscoll et al., 2013). Medical specialists became advisory consultants who provided specialty health care and returned customer-owners to the medical home as quickly as possible. Case managers, certified medical assistants, and administrative support became part of integrated primary care teams. Customer-owners were also granted same day access to appointments with their medical home. Behavioral health consultants, psychiatrists, midwives, and pharmacists integrated into primary care clinics and fostered multi-dimensional wellness with minimal stops for customer-owners. In addition, SCF services were provided within outpatient clinics in pediatrics, dental, optometry, complementary medicine, traditional healing, home-based services, and health education services. All SCF employees attended mandatory customer service and communication training, and medical team performance was compared with external benchmarks like Healthcare Effectiveness Data and Information Set (HEDIS).

Table 1
Southcentral Foundation's Vision, Mission, and Key Points

Vision	Mission	Key Points
A Native Community that enjoys physical, mental, emotional and spiritual wellness	Working together with the Native Community to achieve wellness through health and related services	Shared Responsibility Commitment to Quality Family Wellness Operational Excellence

SCF provides health services to more than 65,000 AN/AI people in Alaska, representing 229 Alaskan federally recognized tribes (Gottlieb, 2013). The clinical and administrative workforce of more than 2,100 people is 55% AN/AI heritage (Gottlieb & Tierney, 2015). In 2011, SCF received the Malcolm Baldrige National Quality Award in Health Care for its innovative relationship-based health care delivery system and its significant improvements across many key areas, including access to care, clinical performance, and staff turnover. SCF won the Malcolm Baldridge Award again in 2017, the only health care organization to ever win a second time.

History of Research

Health research has occurred within Alaska and with AN/AI people for decades. As with health care, the history of research with AN/AI people in the United States, including Alaska, has not been positive. In fact, AN/AI people have a history of distrust with research (Buchwald et al., 2006; Christopher, 2005; Manson, Garroutte, Goins, & Henderson, 2004). Contributions to this distrust are multi-faceted and are inextricably intertwined with distrust of federal and other non-Native organizations, given their history of forced assimilation, discrimination, and other mistreatment such as that described in health care. Beyond this more diffuse distrust, many AN/AI people and communities believe that some research has been harmful, that most research may have benefited researchers but not AN/AI individuals or communities, and that sharing research results with respondents and communities has been unsatisfactory (Harding et al., 2012; Hiratsuka, Brown, Hoeft, & Dillard, 2012; Williams et al., 2010).

Table 2
Southcentral Foundation Operational Principles

Relationships between customer-owner, family and provider must be fostered <u>and</u> supported

Emphasis on wellness of the whole person, family and community (physical, mental, emotional, & 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

Two research studies in Alaska are often cited as examples of research harmful to the AN community by breaching the trust between researchers and community members: the Alaskan I-131 experiment and the Barrow Alcohol Study. In the Alaskan I-131 experiment of 1956 and 1957, radioactive iodine was injected in 102 AN people by the U.S. Air Force in a study to help understand how humans may acclimatize to cold. In 1993, Congress asked the National Research Council to convene a committee to review the study (National Research Council, 1996). AN community members were concerned about potential negative health risks among participants,

and they speculated that guidelines governing research were not followed. The committee ultimately determined the risk of thyroid cancer was not elevated in participants but acknowledged that the "experiments were conducted without informed consent, even according to standards of the time" (National Research Council, 1996, p. 5). Participants were not fully informed about the nature and potential risks of the iodine injections. In particular, the committee found that children participated without assent or parent consent, elders or other intermediaries solicited consent without proper training, and many of the AN participants believed they were receiving medical care rather than participating in a research study with no expected health benefit.

The second example of often-cited harmful research is the Barrow Alcohol Study. In 1979, researchers outside of Alaska were invited by city officials in Barrow, Alaska, to assess the problem of alcohol misuse and to work with the city to reduce the high rates of alcohol-related violence and accidental deaths. The final report, entitled "The Inupiat, Economics and Alcohol on the Alaskan North Slope," was released simultaneously to the press and to the Barrow community. The press release was picked up by *The New York Times*, which ran a front page story entitled "Alcohol Plagues Eskimos" by Dava Sobel on January 22, 1980. The following is an excerpt from that article, showing sensational, stigmatizing phrasing:

> The Inupiat Eskimos of Alaska's North Slope, whose culture has been overwhelmed by energy development activities, are 'practically committing suicide' by mass alcoholism…The alcoholism rate is 72 percent among the 2,000 Eskimo men and women in the village of Barrow, where violence is becoming the most frequent cause of death as a result of 'the explosive and self-destructive abuse of alcohol,' the researchers said. 'Offshore oil development is expected to peak in 2010 or 2015' … one of the researchers said at a news conference. 'We don't see the Eskimos surviving till then. This is not a collection of individual alcoholics, but a society which is alcoholic, and therefore facing extinction.' (Sobel, 1980)

Tribal leaders, city officials, and community members were angered by the release of results to the media before the community could review and comment (Foulks, 1989). While the language was degrading and stigmatizing, the results were also questionable because measures had not been validated in AN people, and the statistical methods had marked limitations (Guilmet, 1989; Trimble, 1989). After this study, many AN people hesitated to participate in

research, particularly research about sensitive topics like alcohol misuse (Kraus, 1989; Skewes & Lewis, 2016).

Research in Southcentral Foundation's Nuka System of Care

Akin to compacting health care, SCF formally expressed tribal sovereignty over health research in 2005 by enacting a research policy requiring approval of all research that includes SCF customer-owners, occurs within SCF facilities, or involves SCF employees. Research oversight had previously been provided solely by a regional IHS entity, the Alaska Area Institutional Review Board. Per the SCF research policy, an initial evaluation by researchers, medical directors, and vice presidents on an internal Research Oversight Committee provides recommendations and input to the all Alaska Native SCF Board of Directors. The Board of Directors then conducts its own review and approves or disapproves research concepts, proposals, abstracts, and manuscripts before applications for funding, implementation, presentation, or publication. Evaluation criteria include: a) alignment with SCF vision, mission, key points, goals, and objectives; b) quality of research design; c) respect of and collaboration with AN/AI people as partners in research; and d) return of results to the community.

Southcentral Foundation's Research Department

In 2006, SCF took another step in assuming ownership of research by establishing a research department. As part of the Nuka System of Care, the SCF Research Department is charged with conducting research on priorities identified by the AN/AI community and tribal, clinical, and administrative leaders as epitomized in corporate objectives and guides by SCF's mission, vision, key points, and operational principles. Through internal and external funding from the National Institutes of Health, the Research Department effectively expanded the number of research projects that address multiple SCF corporate objectives, including reductions in diabetes; cancer; cardiovascular disease; obesity; oral health; substance misuse; suicide; and domestic violence, child abuse, and neglect. Of 20 permanent SCF Research Department employees, 15 have AN/AI heritage, not counting available AN/AI intern positions at the pre-baccalaureate, baccalaureate, and graduate levels. In further engagement with the community, the SCF Research Department conducted qualitative research asking AN/AI people to consider

the cultural and ethical implications of different types of research, such as genetic research, and to comment upon research processes like informed consent, data and specimen storage, and return of results (Avey et al., 2016; Hiratsuka, Brown, & Dillard, 2012; Shaw, Robinson, Starks, Burke, & Dillard, 2013; Starks, Shaw, Hiratsuka, Dillard, & Robinson, 2015; Woodahl et al., 2014). Subsequently, the SCF Research Department implemented improvements in the informed consent process and the storage of data and specimens in local repositories with AN oversight (Hiratsuka, Brown, & Dillard, 2012; Hiratsuka, Brown, Hoeft, & Dillard, 2012). The SCF Research Department has continued to prioritize engagement around research in general and aspires to provide timely, respectful, and relevant results dissemination guided by best practices in CER with AN/AI people.

Best Practices in Community Engaged Research

Descriptions of Community Engaged Research (CER) have become increasingly prominent in the literature; in some cases, CER is deemed compulsory for research conducted with AN/AI communities (James et al., 2014). The CER literature includes descriptions of AN/AI community members being receptively engaged in research from the inception of a study through to its completion, including defining research priorities, developing research questions, designing research instruments, collecting data, and participating in data analysis and interpretation. Nevertheless, collaborative results dissemination is an element of engagement that appears to be consistently overlooked or otherwise ineffectively executed in research with the general population (Chen, Diaz, Lucas, & Rosenthal, 2010) with only a few examples in research with AN/AI people.

Many academic researchers submit research results to peer-reviewed journals as a primary method of disseminating their findings, which limits their audience to the academic community (Chen et al., 2010; MacKenzie, Christensen, & Turner, 2015; Smylie, Kaplan-Myrth, & McShane, 2009). This practice also may limit the applicability of results to address local problems given that community perceptions of health may differ from that of the research community. The community systems of sharing information among one another may also vary from that of the scientific community (Smylie et al., 2009).

Collaborative community engaged results dissemination involves identifying relevant audiences; creating messages appropriate for those audiences using methods such as summaries,

community presentations, and other media (i.e., visual, radio, advertisements); and engaging community members in developing and sharing information (McDonald et al., 2016; McShane, Smylie, Hastings, & Martin, 2006; Pufall et al., 2011). Moreover, dissemination efforts that lean toward useful translation of research for planning and decision-making, rather than simply making information comprehensible to a lay audience are more beneficial to community participants (Bowen & Martens, 2005).

Effective CER dissemination considers the importance of "multidirectional" information exchange, which includes establishing trusting alliances and a setting that allows for comfortable communication, so that research information is relevant to the community (Bowen & Martens, 2005; Elsabbagh et al., 2014). Relevancy to AN/AI communities includes disseminating results that take into consideration local context (Legaspi & Orr, 2007; McDonald et al., 2016; Timmons et al., 2007), appropriate language, information that is both practical to researchers and community members (MacKenzie et al., 2015), and information that considers local values with incorporation of AN/AI knowledge and expertise as integral parts of the process (Legaspi & Orr, 2007; Rivkin et al., 2013). Direct communication can strengthen community trust in research, while concurrently enhancing researchers' understanding of community concerns and perceptions of research (Legaspi & Orr, 2007; McDavitt et al., 2016).

The CER literature clearly shows that disseminating research results in a meaningful way to communities and particularly AN/AI communities is easier to describe than accomplish. Constraints within AN/AI and other communities include issues related to resources, such as a lack of funding or time; difficulties engaging community members (James et al., 2014; Legaspi & Orr, 2007; Rivkin et al., 2013); reaching all relevant stakeholders (Chen et al., 2010; Rivkin et al., 2013); and a lack of guidelines about involving community members in research and results dissemination (Koster, Baccar, & Lemelin, 2012; McDonald et al., 2016).

Southcentral Foundation's Community Engaged Research

Per the review of CER and other literature about disseminating research results, the SCF Research Department has implemented many best practices. SCF uses multi-modal communication to engender community engagement and to share findings. At the annual gathering for all SCF customer-owners, the Research Department staffs booths and discusses the displays of current and prior study information with attendees. SCF participates in a biannual

research conference for tribal leaders and the AN/AI community that highlights research with AN/AI people. The Research Department staff writes articles for the SCF customer-owner newsletter about upcoming, ongoing, and completed research studies. Staff also produces a series of articles about the composition and focus of the Research Department and the SCF research approval process in the customer-owner newsletter. The SCF website also contains information about Research Department projects.

For individual research studies, the SCF Research Department produces newsletters and other written products, like brochures, that describe the study, provide updates, and summarize results. These products are provided to individual AN/AI participants, displayed in lobbies, and distributed at other SCF and ANMC locations. For studies open to recruitment, the SCF Research Department devises the promotional fliers, newsletters, content for social media, such as Facebook and Twitter, and content for the waiting room computer screens in SCF clinic areas. SCF Research Department staff also present studies and results in meetings with tribal leaders and community members, particularly when studies involve regions outside of Anchorage.

The SCF Research Department also informs employees within the Nuka System of Care, more than one-half of whom are of AN/AI heritage, of its activities. The SCF new hire orientation includes a description of the Research Department. The SCF Intranet, accessible to SCF employees, contains information on Research Department projects. The SCF Research Department staff also writes articles for employee newsletters. In addition to managing ongoing submissions of concepts, proposals, abstracts, and manuscripts of studies relevant to SCF and ANMC, the Research Department also provides quarterly, written updates about all studies to the SCF Research Oversight Committee and the SCF Board of Directors (Hiratsuka et al., 2017). The SCF Research Department also verbally presents study updates and results within quality improvement committees or other venues as determined by specific SCF Divisions. For studies in which a new intervention is being tested, the SCF Research Department collaborates with the study team to determine the appropriate content and venue for disseminating results.

Southcentral Foundation's Ongoing Challenges in Research Engagement

Despite the intentions and activities of the SCF Research Department, customer-owners request more information about research actively being conducted, data collection and other progress updates, study results, and whether indicated changes in health care delivery are made

in a timely manner (Boyer et al., 2011; Gottlieb, 2013; Hiratsuka, Brown, & Dillard, 2012; Hiratsuka, Brown, Hoeft, & Dillard 2012; Woodahl et al., 2014). These expectations for information exchange across the full lifespan of research projects clearly require active engagement well beyond approval of a scientific manuscript or a final report by a tribal government (Jetter, Yarborough, Cassady, & Styne, 2015; Oetzel et al., 2015). The SCF Research Department has identified the following communication barriers as ongoing challenges in engaging and disseminating research findings to AN/AI people.

Communication Barrier – Population Size and Distance

One challenge is the large number and vast geographical distribution of AN/AIs in the southcentral region. SCF currently serves AN/AI people who live in a geographical area that spans more than 100,000 square miles. SCF customer-owners live in diverse environments, ranging from small, remote villages or towns to Alaska's largest city; all locales have varying access to mail, internet, and cell phone service. This presents an obstacle to sharing results through the postal service or electronically. While the SCF Research Department displays study results in person at community events, the number of customer-owners who visit the booths, and the time needed to adequately discuss the results with visitors, limits the effectiveness of this approach to communicating information. Similarly, while research results are periodically displayed on the primary care waiting room computer screens, the viewership is limited to those customer-owners waiting for appointments.

Within the Nuka System of Care, a challenge to disseminating results is the increasing number of SCF employees (2,100) and programs (85). Although the number of SCF employees aware of research activities increased 15% between 2014 and 2015, according to an internal survey, 50% of employees in 2015 indicated they were unaware of research activities at SCF. While the SCF Research Department presents studies and results in person at various meetings across the agency, and electronically through the SCF Intranet and employee newsletter, these approaches are limited in their reach.

Communication Barrier – Jargon

The absence of non-technical communication training for scientific researchers also contributes to SCF's challenge in engaging with and disseminating results to the community.

Research training predominantly focuses on technical writing skills to prepare funding applications and scientific manuscripts, with minimal attention paid to communication strategies for non-scientific audiences. In informal and formal discussions with the AN/AI community members and SCF's Nuka training staff, the SCF Research Department has altered its communication approach for sharing results with the community. This includes reducing scientific wordiness, using standard lay-reader level text, and de-emphasizing detailed technical methods sections. SCF Research Department staff provides additional information, such as how the study came to fruition, how the results may or may not be shared with providers and the health care system, more information about the researcher, and how information will be compiled and shared. This is an ongoing process for the SCF Research Department as it continues to explore and modify its definitions of appropriate content, clarity of content, proper level of detail, and reader comprehension.

SUMMARY

The history of how research has been conducted and how health care has been provided to AN/AI people in Alaska has contributed to distrust and dissatisfaction. We have described how SCF has assumed ownership of its health care system and embedded research within the system to maximize alignment and benefit for AN/AI people. Although the SCF Research Department has prioritized meaningful communication with community members around research, the current engagement and dissemination activities have been limited in reach and satisfaction. As existing literature provides minimal guidance beyond best practices already implemented, the SCF Research Department conducted the Alaska Native Research Forum. The following article describes the Forum in more detail, including a description of three case studies and a summary of recommendations for researchers to consider and implement.

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