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FOREWORD

We are delighted to showcase a unique process for reaching out to, engaging, and disseminating research conducted among Alaska Native people. The Southcentral Foundation, notably its Research Department, led by Dr. Denise Dillard and her colleagues – the authors of this special issue − is widely respected for its deep commitment to pursuing research relevant to its customer/owners. Indeed, simply referring to their patient population in this fashion underscores the alignment of their mission, values, and actions. Frankly, I know of no other entity, tribal or otherwise, so fully dedicated in principal as well as practice to ensuring that its research is driven by stakeholders, that the results are translated into terms meaningful to them, that the findings reflect their perspectives, that the attendant insights are applied with local benefit, and that this work is undertaken in a scientifically rigorous manner that contributes to our understanding of the health and well-being of this special population. The articles herein testify to the effort required of such work and the potential return on investment for all participants.

Unfortunately, much of today's conversation about outreach to, engagement of, and dissemination among Native communities proceeds at a level of abstraction that offers little guidance about actual process. Not so here. The authors describe in detail the nature of their research, steps taken to communicate findings to key stakeholders, the latter's reactions, and implications for this process. Their candid discussion of the challenges that arose during this endeavor represents a refreshingly authentic analysis of a difficult subject, the mechanics of which are often glossed over in the rush to exhort others to engage tribal communities. Of particular value is the authors' reflection on how the communication strategies available to them through the Southcentral Foundation can be mobilized to maintain the momentum of their initial efforts and to reinforce the reciprocity as well as transparency that characterized this undertaking. The lessons learned, and shared in the pages to follow, are important ones. Thank you for stretching yourselves beyond the typical role of researcher-as-scientist to illustrate these lessons and the wisdom contained therein.

Spero M. Manson, PhD
Editor-in-Chief

AN INTRODUCTION TO THE SPECIAL ISSUE ON THE ALASKA NATIVE HEALTH RESEARCH FORUM

Denise A. Dillard, PhD

This special issue of *American Indian and Alaska Native Mental Health Research* focuses on a critical but often neglected aspect of collaborative research: how to share research and research findings in meaningful ways with Alaska Native and American Indian (AN/AI) community members. In May 2016, the Southcentral Foundation (SCF) Research Department conducted the Alaska Native Health Research Forum. The primary purpose of the Forum was to obtain feedback on the outreach and dissemination strategies SCF Research Department uses to communicate with community members.

Beyond this introduction, the special issue consists of three sections. Section I describes the background information shared with Forum attendees, the structure and content of the Forum itself, and the methods used to gather community feedback. Section II depicts three SCF research studies that disseminated results differently, along with community feedback about clarity of results, sufficiency of information, and the degree to which information was presented in an interesting way. The three research studies concern dissemination of results from a T-SBIRT (i.e., trauma-focused screening, brief intervention, and referral to treatment) process, a stakeholder-driven decision support tool to aid in depression management, and interest in pharmacogenetic research. Section III includes feedback from the community about the Forum itself, a summative evaluation, and recommendations to improve communication with AN/AI people about research. We expect many of our lessons learned are applicable in other research settings where a goal is to meaningfully engage community members in collaborative research.

ACKNOWLEDGEMENTS

SECTION I

Section I of this special issue describes the background information shared with Alaska Native Health Research Forum attendees, the structure and content of the Forum itself, and the methods used to gather community feedback.

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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APPROACH AND METHODS OF THE 2016 ALASKA NATIVE HEALTH RESEARCH FORUM

Vanessa Y. Hiratsuka, PhD, MPH; Jaedon P. Avey, PhD; Julie A. Beans, MPH; Lisa G. Dirks, MLIS, MAdm; Karen Caindec, BSBA; and Denise A. Dillard, PhD

Abstract: Southcentral Foundation, a tribal health organization serving Alaska Native and American Indian (AN/AI) people in southcentral Alaska, convened the Alaska Native Health Research Forum (Forum) for AN/AI people in May 2016. The purpose of the Forum was to obtain AN/AI community member feedback about sharing health research results. This article describes the funding mechanism that provided resources for the Forum and other factors that were considered when designing the Forum. This is followed by a description of how attendees were invited, the audience response system, and process used to collect quantitative data on participants and qualitative feedback from small group discussions with Forum attendees. Finally, we describe the quantitative and qualitative data analysis processes used to evaluate responses.

In the previous article in this special issue (Dillard et al., 2018, "Challenges in Engaging and Disseminating Health Research Results"), we describe the larger context explaining why the Alaska Native Health Research Forum (Forum) was held. This article describes the funding mechanism that provided resources for the Forum and other factors that were considered when designing the Forum. We describe how attendees were invited, the methods used to collect quantitative and qualitative feedback from Forum attendees, and data analysis strategies. Evaluation of the Forum is also presented in this special issue (Hiratsuka et al., 2018, "Alaska Native Health Research Forum: Perspectives on Disseminating Research Findings").

INTRODUCTION

Funding

In 2012, Dr. Spero Manson of the University of Colorado Denver (UCD) received renewed funding as a Principal Investigator for a National Institute of Minority Health and Health Disparities Comprehensive Center of Excellence. During the third cycle of support, UCD elected to focus on the health impacts of trauma on Alaska Native and American Indian (AN/AI) populations. Funded activities included two research projects in partnership with Southcentral Foundation (SCF) in Alaska and another AI tribal health organization in Oklahoma. Other funded activities included engagement and outreach efforts to enhance the involvement of community members in research. Given the historical mistrust of research and lack of consistency in appropriately sharing research findings, exemplified by Dillard, Caindec, Dirks, and Hiratsuka (2018) in the first article to this special issue, SCF proposed to fund a conference to explore how research results are currently communicated to the AN/AI community and to gain insight into how that effort could be improved.

Purpose of the Forum

The Forum was designed in collaboration with Karen Caindec, Secretary/Treasurer of the SCF Board of Directors; Michael Doyle of the SCF Public Relations Department; and Drs. Spero Manson and Candace Fleming from UCD. Although the purpose of the Forum was to obtain feedback about sharing health research results, a review of the literature and past research communication with community members suggested the inclusion of additional critical discussion topics, including research mistrust due to past unethical research practices and contemporary AN/AI community level research review practices (Bowekaty, 2002; Bromley, Mikesell, Jones, & Khodyakov, 2015; Filippi et al., 2012; Gottlieb, 2013; Guillemin et al., 2016; Hiratsuka, Brown, Hoeft, & Dillard, 2012). To address the issue of research mistrust in AN/AI communities and to foster open, reflective discussion, an important starting point for the Forum was to acknowledge the history of unethical and harmful research in the AN/AI community. Additionally, to inform the attendees about the context of current research at SCF, we invited SCF Board Member Karen Caindec to describe the SCF Research Department as well as the SCF Nuka System of Care (Gottlieb, 2013; Gottlieb, Sylvester, & Eby, 2008; Gottlieb & Tierney,

2015). Throughout the Forum, presenters emphasized the deliberate, extensive research protections currently in place and linkages to the SCF mission and vision, which the AN community helped to create.

It was also important to showcase several SCF Research Department projects to illustrate SCF's research portfolio of significant medical and behavioral health topics. In addition, we wanted to obtain feedback on different ways to share information across topics. We decided to use three case studies, which varied by topic and method of dissemination, as a strategy for gaining insight from attendees on methods that work and that do not work. In the first case study, we briefly presented the findings of a UCD Comprehensive Centers of Excellence Research Project, *Screening, Detection, and Management of Trauma in Primary Care,* and a brochure describing the health effects of trauma and potential support options available at SCF. In the second case study, we presented findings of a decision-support tool for depression that was developed with customer-owners and staff and pilot tested in SCF primary care clinics (Starks, Shaw, Hiratsuka, Dillard, & Robinson, 2014). In this instance, we distributed a double-sided handout that summarized the study, which was followed with group discussions to obtain feedback on the document. After the discussions, we delivered an in-depth oral presentation to provide attendees with additional information on decision support tool findings. For the third case study, attendees were shown an IGNITE presentation (O'Reilly, 2015) on pharmacogenetics research at SCF and a newsletter that provided a brief summary of project findings.

Purpose of Data Collection

We sought to balance collecting detailed feedback with keeping the Forum interactive and enjoyable for attendees. The duration of the Forum was an intensive 3.5 hours to accommodate community members' schedules and to avoid attendee fatigue (Figure 1). To maximize attendee feedback, presentations were limited to 15 minutes to allow 30 minutes for discussion of each case study. We gathered quantitative feedback with a computerized audience response system with predetermined response sets to maximize the small group discussion time. After each case study, we divided attendees into 6-8 person groups and introduced a set of semi-structured facilitated discussion questions to obtain qualitative input.

Finally, we wanted to understand more about individuals who attended the Forum, including basic demographic information, and to assess their satisfaction with this type of venue.

Attendees were asked about participation in current or prior research studies; exposure to written SCF products, such as newsletters and pamphlets; familiarity with electronic media, such as the SCF corporate website and Facebook page; and to comment on the Forum itself. These findings are available elsewhere in this special issue.

METHODS

Recruitment

Attendee recruitment was open for approximately six weeks from April 2016 to the date of the event, May 13, 2016. The SCF Research Department utilized fliers posted in SCF clinic waiting rooms and lobbies, as well as electronic media, SCF's official corporate Facebook page, SCF's community newspaper, and SCF's staff newsletter. Recruitment materials contained information about the purpose of the Forum, a phone number for inquiries about the Forum, and a link to the Forum registration website. The SCF Research Department also staffed a table in the SCF Primary Care Center on weekday afternoons approximately three weeks prior to the event. Because the event was intended for AN/AI adults, individuals who expressed interest verified AN/AI heritage and ability to attend the entire Forum before being registered and given instructions. Interested individuals also registered in person the day of the event. A total of 42 people registered for the Forum and 31 individuals participated. Complete respondent descriptions are provided elsewhere in this special issue.

Audience Response System

Audience response systems (ARS) are an innovative way to involve community members in presentations by posing questions to audience members during the presentation. Various ARS have been used to obtain data in community-based participatory research initiatives and have been well received by AN/AI people (Gamito, Burhansstipanov, Krebs, Bemis, & Bradley, 2005; Subrahmanian et al., 2011) and other diverse community groups (Boscardin & Penuel, 2012; Cain & Robinson, 2008; Davis et al., 2012; Rodriguez, Torres, & Erwin, 2013; Vohra et al., 2014). The ARS is a computer-assisted tool that includes handheld keypads linked wirelessly to a computer system and an audiovisual display (Cain & Robinson, 2008). The keypads allow individuals to respond in real time to multiple choice questions presented in a PowerPoint

presentation format (Gamito et al., 2005). The audience selects a numeric response by pressing the corresponding number on the keypads. The ARS software stores individual data in a database, tallies results, and displays the number of responses and group level data in real time in the PowerPoint presentation on screen (Davis et al., 2012; Gamito et al., 2005).

Quantitative Feedback

At the start of the Forum, SCF Research Department staff taught attendees how to use the ARS handheld device and requested that attendees use the same keypad throughout the event to maintain data consistency. All questions or statements presented via ARS were read aloud to the participants. At the start of the Forum, the ARS was used to collect demographic and pre-engagement data and at the conclusion of the event, to assess post-engagement and Forum satisfaction. Additionally, the ARS was used to query responses from attendees during the presentation of each of the three case examples. Participant demographic information was linked to the ARS responses at the start of the Forum. Demographic questions included sex, age, education level, length of receipt of SCF health care, and whether they have participated in research. Pre-engagement questions with a four-point Likert response (4 = *strongly agree*, 3 = *agree*, 2 = *disagree*, 1 = *strongly disagree*) were asked on awareness of research studies. Attendees were also asked about their interest in learning more about research studies at SCF with the same four-point Likert response scale.

Within each case study presentation, attendees were asked to rate the following items on a four-point Likert scale. Items included: "The presentation was clear"; "The amount of information presented was about right"; and "The results were presented in an interesting way." Although the timing of these questions may have varied within each case study, these same three questions were asked via the ARS.

At the end of the Forum, the following questions were asked again to assess changes in responses after presentations by SCF Research Department staff and small group discussions with customer-owners: "I am aware of research studies happening at Southcentral Foundation"; "I am aware of what was learned from research studies that happened at Southcentral Foundation"; "I would like to learn more about what was found from research studies that happened at Southcentral Foundation"; and "I would like to learn more about how results changed how Southcentral Foundation staff deliver health care." Forum satisfaction and results

dissemination preferences were assessed via questions using the same four-point Likert scale. Questions on Forum satisfaction included: satisfaction with Forum space, duration of the Forum, staff friendliness, satisfaction with using the ARS handheld keypads, and ratings as to whether the small group discussions were a good way to share thoughts.

Next, the following series of questions were asked using a different four-point Likert response option (4 = *A lot*, 3 = *Some,* 2 = *A little*, 1 = *Not at all*) to assess how the Forum impacted thoughts on health research: "The Forum challenged my thinking about health research"; "My understanding of health research increased due to the Forum"; and "My willingness to participate in health research at SCF increased due to the Forum."

Finally, attendees were asked four questions about how they would like to learn about SCF research studies and research results and to identify two preferences for results dissemination given the following choices: posters/fliers, email, social media (like Facebook, Twitter, Instagram, Google+), Anchorage Native News (SCF's community newspaper), myANMC (patient information portal), and postal mail. Finally, participants were asked to rate the usefulness of the Forum.

Qualitative Feedback

Four discussion groups, each with 6-8 attendees, provided feedback on each case study presentation. Discussion groups also included two SCF Research Department staff members, performing the roles of discussion facilitator and note taker. The groups were asked to respond to the following six questions: "Why should the results be shared?"; "How should results be shared?"; "Who should hear about the results?"; "What results should be shared?"; "Where should results be shared?"; and "When should results be shared?". Discussion facilitators allowed attendees to respond to questions as they were posed and to ask questions of the researchers about the presentation. Optional unstructured probes following the six questions were not consistent across groups because probes were dependent on the groups' discussion.

Data Collection and Statistical Methods

The ARS system stored responses in a database. Participant responses were exported and summarized with descriptive data about participants cross-tabulated by responses and questions. Paired independent *t*-tests assessed changes in responses to the four questions asked at both the

start and conclusion of the Forum concerning how participants would like to learn about SCF research. Notes of each discussion group were analyzed for content by a single researcher with training in qualitative research. After reading through discussion notes multiple times, data were hand-coded, organized into a coding schema, and clustered into unified themes. Themes were reviewed and verified for completeness and accuracy by two additional researchers with thematic results presented by case study elsewhere in this special issue.

CONCLUSION

The approach and methods for the Forum elicited intensive discussion and feedback presented elsewhere in this special issue. Each of the three case studies that were presented at the Forum are described with the nature of the study, the dissemination products presented, results of quantitative and qualitative assessments, and discussion about lessons learned, limitations, and next steps, as appropriate. Also described elsewhere in the special issue is the overall Forum evaluation (Hiratsuka et al., 2018, "Alaska Native Health Research Forum: Perspectives on Disseminating Research Findings"). The final paper in this special issue provides lessons learned through the Forum with attention to AN/AI community level communication (Shane et al., 2018, "Future Directions in Disseminating Research Findings to Urban Alaska Native People").

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Figure 1: Forum agenda

Alaska Native Research Forum
Southcentral Foundation Research Department
Center for American Indian and Alaska Native Health
University of Colorado - Denver
May 13, 2016
Anchorage, AK

Venue: SCF - Nuka Wellness and Learning Center - Tribal Drum
4085 Tudor Centre Drive, Anchorage, AK 99508

Time: May 13th 1:00PM – 4:30PM

Friday, May 13th

1:00 – 1:05	Welcome (Alexandria Mullan)
1:05 – 1:15	Pre-conference evaluation
1:15 – 1:30	Overview of SCF Research Department mission and vision, tribal research review process, and goal of improving dissemination (Karen Caindec)
1:30 – 1:45	SCF Public Relations (Michael Doyle)
1:45 – 2:00	Screening, Detection, and Management of Trauma in Primary Care (Jaedon Avey)
2:00 – 2:30	Feedback session
2:30 – 2:45	Break
2:45 – 3:00	Engaging Stakeholders to Develop and Pilot a Decision Support Tool for Depression (Lisa Dirks)
3:00 – 3:30	Feedback session
3:30 – 3:45	Pharmacogenetics (Julie Beans)
3:45 – 4:15	Feedback session
4:15 – 4:20	Post-conference evaluation
4:20 – 4:30	Wrap up (Alexandria Mullan)

ALASKA NATIVE HEALTH RESEARCH FORUM: PERSPECTIVES ON DISSEMINATING RESEARCH FINDINGS

Vanessa Y. Hiratsuka, PhD, MPH; Julie A. Beans, MPH; Lisa G. Dirks, MLIS, MAdm; Jaedon P. Avey, PhD; Karen Caindec, BSBA; and Denise A. Dillard, PhD

Abstract: In May 2016, Southcentral Foundation (SCF), a regional tribal health corporation based in Anchorage, Alaska convened a half-day health research forum for Alaska Native and American Indian community members to obtain feedback on communication of research findings. Thirty one individuals attended the Forum and 22 completed a pre and post survey. Respondents found the Forum to be a useful method to learn about research projects and their willingness to participate in health research reportedly increased because of the event. Forum attendees also endorsed use of direct mail, electronic mail, and messages via an electronic health record patient portal as communication methods for health researchers to inform potential participants about research studies occurring at SCF and for return of individual and community level results.

In the previous article in this special issue (Hiratsuka, et al., 2018, "Approach and Methods"), we provide a description of the conduct and data collection processes occurring at the Alaska Native Health Research Forum (Forum). This article describes summary findings from the quantitative data collection from attendees at the Forum.

INTRODUCTION

Past conduct of research in Alaska Native (AN) and American Indian (AI) communities has been consistently described as adversarial, in part because of the lack of community involvement in the research process (Bowekaty, 2002; Brugge & Missaghian, 2006; Christopher, 2005; Filippi et al., 2012; Hodge, 2012; Mariella, Brown, Carter, & Verri, 2009; Mello & Wolf, 2010; Quigley, 2006; Struthers, Lauderdale, Nichols, Tom-Orme, & Strickland, 2005). In the past decade, AN tribal health organizations and AN communities have implemented research approval processes (Hiratsuka et al., 2017). AN health organizations and AN communities also have conducted or partnered with academic researchers as co-investigators to develop, conduct, and apply health research findings within their settings (Hiratsuka, Brown, & Dillard, 2012; Hiratsuka, Brown, Hoeft, & Dillard, 2012; Lewis & Boyd, 2011; Shaw, Robinson, Starks, Burke, & Dillard, 2013; Smith, 2013). In the process of conducting research, it is clear the broader AN community is not fully aware of the community level research review process and that AN community members have interest but lack opportunities to comment on research at each step in the process (Hiratsuka, Brown, & Dillard, 2012; Shaw et al., 2013).

Community-based participatory research methods require an equal valuing of community beliefs with principles of health research, in which engagement, mutual understanding, and communication are constants throughout the research process (Bromley, Mikesell, Jones, & Khodyakov, 2015; Burhansstipanov, Christopher, & Schumacher, 2005; Oetzel et al., 2015; Pearson, Parker, Fisher, & Moreno, 2014; Shore, Drew, Brazauskas, & Seifer, 2011). Transparency in the process of research is an ideal that has yet to be fully realized in research with AN communities (Hiratsuka, Brown, Hoeft, & Dillard, 2012). A large qualitative study of AN peoples' views on health research found that many AN people, including tribal leaders, wanted more information on the process and intent of community review of health research utilizing biological specimens (Hiratsuka, Brown, & Dillard, 2012; Hiratsuka, Brown, Hoeft, & Dillard, 2012). They also wanted to know how research findings would be used to improve AN health outcomes since that was the main reason stated for AN participation in health research with biological specimens (Hiratsuka, Brown, & Dillard, 2012; Hiratsuka, Brown, Hoeft, & Dillard, 2012).

METHODS

Southcentral Foundation (SCF), an AN tribal health organization, has developed the Research Approval Process to oversee research conducted with the AN/AI in their community (Hiratsuka et al., 2017). At SCF, the AN/AI health care recipients are not referred to "patients," but rather as "customer-owners." SCF's tribal review process requires researchers to write a summary of research findings for lay readers for use in its community newsletters and social media. Ideally, interested community members would be involved throughout the entire research process, which could lead to results that are actionable in the community as well as in clinical settings. The community discussion process affords the research team an opportunity to understand how the community sees the utility of the results within the larger context.

The Forum was convened to obtain feedback on outreach and dissemination strategies used by the AN health system to communicate research findings with community members. The SCF Research Oversight Committee deemed all engagement activities of the Forum to be Quality Assurance/Quality Improvement, a non-research designation, thus precluding IRB management. A detailed description of attendee recruitment, qualitative and quantitative data collection methods, and data analysis strategies are described elsewhere in this special issue (Hiratsuka et al., 2018, "Approach and Methods"). This article focuses on summarizing the quantitative feedback.

RESULTS

Forum Participants

A total of 31 AN/AI adults attended the 3.5-hour Forum. As noted in *Approach and Methods* located in this special issue, all attendees were provided and willing to use the audience response system (ARS) keypads which were used for pre- and post-survey data collection. Twenty-two respondents provided pre- and post-responses to these questions. The majority of attendees were female (68%), between the ages of 40-59 years old (43%) and reported some college education but not being a college graduate (42%; Table 1). The majority had received health care from SCF for longer than five years (55%), but there were individuals who received SCF health care for less than one year (28%). Most participants reported past participation in

research (82%), and the majority strongly agreed or agreed they would like to learn more about research studies happening at SCF (90%).

Table 1
Characteristics of 31 Participants in a Forum on Research in the AN/AI Community

Characteristic	N	%
Sex		
Female	17	68%
Male	8	8%
Age		
18-29 years old	6	20%
30-39 years old	4	13%
40-59 years old	13	43%
60 years old or older	7	23%
Employment at Alaska Native Medical Center campus		
Yes	4	13%
No	27	87%
Education level		
Some high school or less	2	7%
High school graduate	9	29%
Some college	13	42%
College graduate	4	13%
Trade or vocational school	3	10%
Length of receipt of health care from SCF		
Less than a year	8	28%
Over a year but no more than 3 years	4	14%
For 3-5 years	1	3%
Longer than 5 years	16	55%
Past participation in research		
Yes	18	82%
No	4	18%
I would like to learn more about research studies happening at Southcentral Foundation.		
Strongly disagree	1	3%
Disagree	2	7%
Agree	9	30%
Strongly agree	18	60%

Attendee Evaluation Responses

At the conclusion of the Forum, attendees were asked a series of questions on event satisfaction and information learned (Table 2). Attendees reported high satisfaction with the Forum facilities (80%), the friendly staff (93%), having enough time for the event (83%), using ARS (87%), and most attendees (87%) reported feeling that the small group discussions were a good way to share thoughts. The majority reported that they felt their understanding of health

research at SCF increased because of the event, with 50% reporting their understanding increased a lot and 30% reporting their understanding increased some.

When asked how attendees would like to learn about research studies at SCF, the top answer was by direct mail (35%), followed by email (17%), and *myANMC* (17%), the patient information portal. Attendees were then also asked their second choice; the responses were close between posters (28%) and direct mail (24%). Attendees were also asked how they would like to learn about research results at SCF. The top answer was direct mail (59%), followed by *myANMC* (15%), and the *Anchorage Native News* (15%), SCF's community newspaper. As to second choice in how they would like to learn about research results, 40% responded they would like posters/fliers, followed by direct mail (20%).

Table 2
Post-Forum Participant Responses

Question	N	%
I am satisfied with the forum space.		
Strongly disagree	2	7%
Disagree	1	4%
Agree	8	29%
Strongly agree	17	61%
There was enough time for the forum.		
Strongly disagree	0	0%
Disagree	5	17%
Agree	9	31%
Strongly agree	15	52%
The forum staff were friendly.		
Strongly disagree	2	7%
Disagree	0	0%
Agree	2	7%
Strongly agree	25	86%
I like using the handhelds.		
Strongly disagree	4	14%
Disagree	0	0%
Agree	6	21%
Strongly agree	19	66%
The small group discussions were a good way to share my thoughts.		
Strongly disagree	2	7%
Disagree	2	7%
Agree	8	27%
Strongly agree	18	60%
The event challenged my thinking about health research.		
Strongly disagree	13	43%
Disagree	9	30%
Agree	5	17%
Strongly agree	3	10%

Table 2 continued
Post-Forum Participant Responses

Question	N	%
My understanding of health research at Southcentral Foundation increased due to the event.		
A lot	15	50%
Some	9	30%
A little	3	10%
Not at all	3	10%
How would you like to learn about research studies happening at Southcentral Foundation?*		
Posters/fliers	4	14%
Email	5	17%
Social Media (like Facebook, Twitter, Instagram, Google +)	2	7%
Anchorage Native News	3	10%
myANMC	5	17%
Mail	10	35%
What is your second choice in how you would like to learn about research studies happening at Southcentral Foundation?		
Posters/fliers	8	28%
Email	4	14%
Social Media (like Facebook, Twitter, Instagram, Google +)	4	14%
Anchorage Native News	5	17%
myANMC	1	3%
Mail	7	24%
How would you like to learn about results from research at Southcentral Foundation?*		
Posters/fliers	0	0%
Email	3	11%
Social Media (like Facebook, Twitter, Instagram, Google +)	0	0%
Anchorage Native News	4	15%
myANMC	4	15%
Mail	16	59%
What is your second choice in how you would like to learn about results at Southcentral Foundation?		
Posters/fliers	12	40%
Email	4	13%
Social Media (like Facebook, Twitter, Instagram, Google +)	3	10%
Anchorage Native News	4	13%
myANMC	1	3%
Mail	6	20%
Willingness to participate in health research at Southcentral Foundation increased due to the event.		
A lot	23	77%
Some	4	13%
A little	1	3%
Not at all	2	7%
Overall forum content and information is useful to me as a customer-owner.		
Strongly disagree		
Disagree	3	11%
Agree	0	0%
Strongly agree	12	43%
	13	46%

* Respondents were asked to "please pick your top answer."

Four questions were asked of participants at the start and end of the event on a four-point Likert scale, ranging from 1 (*Strongly disagree*) to 4 (*Strongly agree*). As noted in *Approach and Methods* located in this special issue, a two-tailed paired *t*-test was conducted on ARS pre- and post-responses. When asked about awareness of research studies at SCF, the pre-event mean response was 3.2 and after the event was 2.9 ($p = 0.07$), indicating that respondents had less awareness of research studies following the Forum. Attendees were asked next about awareness of what was learned from research studies that happened at SCF. The pre-event mean response was 2.5, and the post-event response was 2.9 ($p = 0.18$). Attendees were asked next if they would like to learn more about what was found from research studies that happened at SCF. The pre-event mean response was 3.5, and the post-event mean response was 3.5 ($p = 0.71$). Finally, attendees were asked if they would like to learn more about research results changing health care delivery at SCF. The pre-event mean response was 3.6, and the post-event mean response was 3.5 ($p = 0.74$).

Attendees were also asked about whether their willingness to participate in health research at SCF increased because of the event (Table 2). Most attendees responded that their willingness to participate in research increased a lot due to the event (77%) or some (13%). Finally, attendees were asked if the Forum's overall content and information was useful as a customer-owner, and the majority agreed (43%) or strongly agreed (46%).

DISCUSSION

Survey data indicate the Forum was favorably received by respondents as a method to communicate about multiple research topics. Respondents found the Forum a useful method to learn about research projects, and their willingness to participate in health research reportedly increased because of the event. Only four pre-post event questions were asked of attendees. The small number of respondents providing paired responses ($n = 22$) yielded non-significant findings with the exception of a reported decrease in awareness of findings from research occurring at SCF. This finding could possibly be attributed to attendees becoming aware of the scope of additional research occurring at SCF as the Forum presentations and discussion occurred, creating awareness of research activities that they hadn't known of previously.

At the conclusion of the event, respondents endorsed individual methods of communication about research such as direct mail, email, and patient portal messages for

researchers to share information on research studies happening at SCF and for communication on research results. Forum attendees provided recommendations on implementing community dissemination methods. Recommendations largely focused on one-way flow of information coming directly from the researchers, (McDavitt et al., 2016) leaving room for future inquiry on developing methods at SCF for appropriate two-way communication between researchers and customer-owners. Collaboration with SCF customer-owners might incorporate interactive presentations using ARS. Davis et al. (2012) have suggested that use of ARS within community town hall format events more actively involves people in the research process while maintaining confidentiality (Davis et al., 2012). Participants in the Forum were provided ARS questions/items, and their responses guided the subsequent small group discussions. Gamito et al. (2005) describe a similar process, where community presentations were created with optional slides allowing the presenter to adapt presentations to the audience's preferences. Future AN/AI community level research presentations, including events to disseminate findings and foster community dialogue, would benefit from the inclusion of ARS as a method to encourage real-time two-way communication between community member experts and research experts.

Several models for community engagement in all aspects of the research process have been described in the literature. Whitewater et al. (2016) recently shared a flexible method for engaging community partners where the individual strengths and interests of community members could be honored by inviting them to participate in the research process through a variety of methods. For instance, community members could be asked how they want to participate in the research process: as members of review panels or community advisory boards; as focus group or individual interview participants to elicit feedback on project planning or dissemination; or as research participants in the subsequent study.

Rivkin et al. (2013) provide a framework for collaborative community dissemination in which the community guides all aspects of the research, including sharing findings. Communication within this framework is driven by community interpretation of project findings, thus project findings are placed within community needs and context, which immediately allows for community members to directly address local issues. Inherent in this process is the recognition that community members and tribal entities can remove cultural misunderstandings in interpreting findings and are capable of using research results applicable to local context and priorities.

CONCLUSION

Incorporating multiple, flexible, community-driven points for customer-owner engagement in the research process offers a potential for increasing interaction with researchers. The increased willingness of customer-owners to participate in studies may also increase community-researcher trust. Forum attendees recommended the use of multiple methods for engagement, which could enhance the use of research findings in the SCF clinical setting and the AN community; however, the method for engagement may need to be adjusted based on the research topic and community interest in engagement on the topic.

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SECTION II

Section II of this special issue depicts three Southcentral Foundation research studies that used different results dissemination activities at the Alaska Native Health Research Forum. The section provides descriptions of each study along with community feedback about clarity of results, sufficiency of information, and the degree to which information was presented in an interesting way.

DISSEMINATING INFORMATION ON TRAUMA SCREENING, BRIEF INTERVENTION, AND REFERRAL TO TREATMENT IN A TRIBAL HEALTH SETTING: A CASE STUDY

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Abstract: Exposure to trauma is consistently associated with co-occurrence of behavioral health disorders. Primary care settings are opportune places to screen for traumatic experiences and symptoms, as they are often the initial point of care for behavioral health concerns by the Alaska Native and American Indian (AN/AI) population. In this case study, we examine results dissemination activities at the SCF Research Department-hosted 2016 Alaska Native Health Research Forum (Forum) of a pilot study of a trauma-focused screening, brief intervention, and referral to treatment (T-SBIRT) process for AN/AI adults in primary care. Feedback included audience responses to the presentation delivered at the Forum and recommendations to guide future community dissemination of T-SBIRT results. Attendees (N = 31) found the presentation clear, interesting, and included the right amount of detail. Four broad dissemination themes were identified in discussion groups: 1) share results with everyone; 2) share results in ways that reach all AN audiences; 3) provide a summarized status update at each stage of the study; and 4) use results to improve care for trauma and related symptoms.

The purpose of this case study was to closely examine how to disseminate findings from a pilot test of a T-SBIRT (i.e., trauma-focused screening, brief intervention, and referral to treatment) process at Southcentral Foundation (SCF) to an Alaska Native and American Indian community audience. The current article first describes the pilot test and then focuses on a case study of the dissemination activities at the 2016 Alaska Native Health Research Forum, including the process of tailoring dissemination products for this community audience, the audience's response to the delivered presentation, and audience feedback about future dissemination of T-SBIRT results.

INTRODUCTION

Exposure to trauma is consistently associated with co-occurrence of behavioral health disorders, suicidal behaviors, chronic disease risk factors, and an increase in health care service utilization (Beals et al., 2005; Goldstein et al., 2016; LeBouthillier, McMillan, Thibodeau, & Asmundson, 2015; Neria, Nandi, & Galea, 2008; Schnurr, 2015). AN/AI people experience higher rates of intergenerational trauma, interpersonal violence (Duran et al., 2004; Duran et al., 2009; Ehlers, Gizer, Gilder, & Yehuda, 2013; Evans-Campbell, Lindhorst, Huang, & Walters, 2006; Libby et al., 2005; Malcoe, Duran, & Montgomery, 2004; Manson, Beals, Klein, Croy, & Team, 2005; Saylors & Daliparthy, 2006; Wood & Magen, 2009), and unintentional injury than their non-AN/AI counterparts (Castrodale, 2007; Centers for Disease Control and Prevention, 2013; Edelman, Cook, & Saffle, 2010; Pollack, Frattaroli, Young, Dana-Sacco, & Gielen, 2012). Elevated prevalence leads to higher rates of individuals experiencing multiple traumas, which in turn increases the likelihood of lifetime risks for associated disorders (Beals et al., 2005). To improve trauma-informed care and prognosis is to detect traumatic experiences and post-traumatic stress disorder (PTSD) earlier (Substance Abuse and Mental Health Service Administration, 2014; Ursano et al., 2004). Primary care settings are opportune places to screen for PTSD symptoms given the relationship between traumatic experiences and medical and/or behavioral health problems. These settings also often serve as the initial point of entry for behavioral health care services.

Trauma Screening, Brief Intervention, and Referral to Treatment

In 2012, the University of Colorado Denver (UCD), SCF, and Cherokee Nation Health Services (CNHS) joined in a research partnership to 1) work with key stakeholders to expand current primary care efforts to include trauma-focused screening, brief intervention, and referral to treatment (T-SBIRT) in their respective health care settings and 2) to test the acceptability and feasibility of this new T-SBIRT process. The Center for American Indian and Alaska Native Health at UCD coordinated the study. SCF's Anchorage Native Primary Care Clinic and CNHS's W.W. Hastings Hospital in Tahlequah, Oklahoma were the primary care clinics. Combined, these sites serve nearly 200,000 AN/AI people.

A steering committee of key representatives from each site (two or more clinical providers and one administrator/program director) guided all stages of the research process. The

steering committee developed mutually agreed upon guiding principles to: 1) build on the strengths of AN/AI cultures and communities; 2) use a collaborative, inclusive investigative approach; and 3) do no harm and use research as a positive change agent. Operating by these principles, the research team used an iterative research process commonly used in community-based participatory research (CBPR) projects with the following five distinct steps: 1) identify cycle goals, 2) develop measure/material, 3) collect data, 4) manage and analyze data, and 5) interpret results.

Process Development and Pilot Study

The research team met with stakeholders to develop a screening, brief intervention, and referral process for trauma among AN/AI adults at SCF and CNHS. The steering committee identified three stakeholder groups for primary data collection: health care providers in primary care and behavioral health clinics; administrative, clinical, and tribal leaders; and patients/customer-owners. SCF uses the term "customer-owner" to reflect how tribal members who receive health care services are also owners of the health care system (Gottlieb, 2013; Gottlieb, Sylvester, & Eby, 2008). Recruitment began in January 2013. Trained qualitative researchers completed 24, one-hour individual semi-structured interviews with providers and leaders and a two-hour focus group with 13 patients and customer-owners. The first round of interviews and focus groups included a combined SCF/CNHS sample of 37 participants; the second round included 33, with four lost to follow-up. In the first round, we asked about the types of trauma experienced in the community, the barriers to healing from trauma, personal and community aspects of strength and resilience, and existing services to treat individuals with symptoms related to trauma. In the second round, we presented participants with T-SBIRT pilot options and asked for recommendations about who should conduct trauma screenings, what questions should be asked in screenings, and ways to provide brief intervention and referral to care for those who need it. Data from each round of data collection were analyzed using a thematic network approach (Attride-Stirling, 2001) by researchers from each partnering organization. Using NVivo 9 (QSR International), three researchers coded one transcript to determine agreement on a priori codes based on question constructs then coded the remaining transcripts, meeting to discuss the coding schema, and later developing summaries from coded transcripts.

Four major themes emerged from the first round of data collection: 1) the nature of trauma in AN/AI communities, 2) barriers to healing from trauma, 3) trauma screening concerns, and 4) screening and brief intervention preferences. In the second round, we identified preferences for a trauma-screening instrument and screening process, and four themes for the development of the brief intervention brochure and process emerged: 1) normalization, 2) simplicity, 3) education/resource sharing, and 4) resiliency.

Researchers used this information to select screening questions, draft an intervention brochure, and create a T-SBIRT process in primary care. SCF and CNHS routinely conduct behavioral health screening in primary care for depression and substance use disorders. These screenings are conducted by trained certified medical assistants at SCF and by nurses at CNHS before the scheduled primary care provider visits. Both systems have behavioral health consultants (BHCs) integrated into primary care clinics to provide brief intervention and referral to additional treatment services such as behavioral health urgent response teams, behavioral health specialty care, and various wellness programs.

A pilot of the T-SBIRT process was completed at SCF and CNHS with a combined sample of 99 primary care outpatients. AN/AI adults who came to the clinic for regular provider appointments were invited to participate. If they agreed, after their appointment, they were asked the four-item Primary Care Posttraumatic Stress Disorder (PC-PTSD) Screen about trauma symptoms by a BHC. The BHC (SCF) or primary care provider (CNHS) reviewed the brief intervention brochure with participants, even those who had screened negative in case a family member had experienced trauma, or they were to experience trauma in the future. BHCs and primary care providers tailored the depth of their review of the brochure to participant responses to the screener or interest.

After reviewing the brochure, the BHC referred the participant to additional behavioral health services or scheduled a follow-up appointment, if needed. To determine the acceptability and feasibility of the T-SBIRT pilot process, researchers collected satisfaction surveys from all participants, conducted a medical records review of participant diagnoses and health service utilization in the one year before and three months after screening. A subsample of 41 participants completed a full 90-minute clinical interview (Structured Clinical Interview for DSM-IV-TR Axis I Disorders, Research Version, Non-patient Edition) and a 36-item quality-of-

life survey (World Health Organization Disability Assessment Schedule 2.0) to explore the diagnostic and predictive validity of the screening process.

Dissemination of Research Activities and Results

The steering committee guided dissemination efforts to customer-owners/patients; clinicians; and clinical, administrative, and tribal leaders. Tribal review bodies at SCF and CNHS approved all dissemination activities. An 18-page report of T-SBIRT development findings, along with the interview and focus group guides, were provided to tribal leadership at SCF in January 2014. Formal dissemination of the T-SBIRT development at CNHS has been limited to progress reports to the Cherokee Nation IRB and informal personal communication with interested providers and leaders. Posters on the development of the T-SBIRT process were presented at the 4th Alaska Native Health Research Conference in March 2014 in Anchorage, Alaska, and the 16th International Congress on Circumpolar Health in June 2015 in Oulu, Finland. Full findings of development efforts were published by Hiratsuka et al. (2016) in *The Journal of Behavioral Health Services & Research.*

Following the pilot, a one-page summary of preliminary information and actionable results were presented to SCF vice presidents and providers. The tri-fold brochure used in the pilot's brief intervention was presented to an administrative quality improvement committee at SCF that focuses on trauma-informed services. That committee later adapted the tri-fold brochure for use in SCF's health care system to bolster trauma-related services.

CASE STUDY

Event Overview

The purpose of the Forum was to: 1) provide an overview of health research among Alaska Native people; 2) obtain feedback on outreach and dissemination strategies used by the Alaska Native health system to communicate with community members on tribal health issues and events; and 3) engage in an open dialogue with the community through a showcase of three current health research projects conducted by the SCF Research Department. A total of 31 AN/AI adults attended the 3.5-hour Forum. A thorough description of the Forum, recruitment, attendee eligibility, registration, Forum activities, the audience response system (ARS), data

collection, and data analysis are available in this special issue (see Hiratsuka et al., 2018, "Approach and Methods").

Designing a T-SBIRT Presentation for a Community Audience

The iterative process of designing, drafting, and revising the T-SBIRT presentation for a community audience was extensive, considering the shortened length of the presentation. The presentation was initially drafted to be a 15-20 minute traditional academic presentation to a non-scientific community audience, or as a shortened version of a conference presentation, educational seminar, or colloquium. This type of presentation would allow for comparison of presentation styles with two other topics presented at the Forum. However, because the presentation was reviewed and revised by the SCF study team, most of whom are SCF customer-owners, it was clear that the traditional presentation was too long, not likely to be engaging, and too technical. Thus, the presentation was edited to target a community audience. The number of PowerPoint slides was reduced from 22, to 19, then to 15, and ultimately to 12 slides (Figure 1). Language about "screening, intervention, and treatment" was reduced and, in some instances, replaced with language such as "screen and care for people" to simplify language, to keep the presentation conversational, and to reflect the setting and use of the findings within the AN/AI health care setting.

As the presentation was revised with the customer-owner audience in mind, fewer direct results of the focus groups and interviews were included; rather, staff presented the end result of the qualitative inquiry—the methods of the pilot. Staff did not discuss the research project linearly, as one might present a traditional research project in a conference or academic setting; SCF staff changed the order of the presentation so that the final products of the pilot process (e.g., screening questions, the brochure as an intervention material, and evaluation method) were shown after the description of the problem, leaving the remainder of the presentation to tell the story of how the researchers came to those final products.

Information about the effectiveness of the PC-PTSD and the T-SBIRT process, the predictive validity regarding quality of life, and the clinical utility of the process of engaging people in additional services was not presented because the analysis was still underway and had not yet been approved by the SCF Board of Directors.

Final T-SBIRT Presentation Overview

The final presentation included a description of each research team member with pictures; descriptions of trauma; paraphrased goals of the study; research partners, roles, and a map of data collection sites; steps in the iterative development of the T-SBIRT pilot process (with clip art); an overview of the pilot process and experience of study participants; four PC-PTSD screening questions; review of the development and final content of a tri-fold brochure (Figure 2); data collection methods that examined the acceptability, feasibility, and validity of the process; and preliminary satisfaction data of participants involved in the study (verbal only).

A local, non-AN/AI (White) study team member (JPA) delivered the presentation to the AN/AI audience. The SCF Research Department had identified in multiple previous projects that community audiences prefer to know more about the background of research team members. Thus, after describing the topic of the presentation, but before describing the study team, the presenter briefly described his personal/educational background, his history at SCF, and what drew him to work in this tribal health setting and on this trauma project.

RESULTS

Quantitative Results

Attendees responded that the presentation was clear (92%), the amount of information was about right (78%), and the results were presented in an interesting way (93%; Table 1).

Qualitative Results

Four broad themes were identified from the discussion groups with community members in direct response to the trauma presentation: 1) share results with everyone; 2) share results in ways that reach all AN audiences; 3) provide a status update in summary form at each stage of the study; and 4) use results to improve care for trauma and related symptoms. Although these themes were in direct result to the trauma presentation, it is believed that some individual responses apply more generally to research in a tribal health setting as attendees may have also been responding to the preceding presentation that addressed tribal oversight in research.

Table 1
Research Forum T-SBIRT Presentation Survey Responses

Survey Response	N	%
The presentation about the results was clear.		
Strongly disagree	1	4%
Disagree	1	4%
Agree	14	54%
Strongly agree	10	39%
Amount of information was about right.		
Strongly disagree	1	3%
Disagree	6	19%
Agree	18	58%
Strongly agree	6	19%
The results were presented in an interesting way.		
Strongly disagree	0	0%
Disagree	2	7%
Agree	19	63%
Strongly agree	9	30%

Share Results with Everyone

Attendees reported that they felt that everyone—tribal communities and the "general public"—should hear the results. This theme was near universal. Although everyone should hear results, participants identified key audiences: customer-owners of SCF, SCF providers, tribal partners, and elders and youth in rural tribal communities. The public, AN/AI and local non-Native, was viewed as a good "check and balance" of validity and applicability of research results.

Dissemination of broad themes was recommended with detailed information available for those with questions. For example, research activities and results of research occurring in Anchorage may be of interest to individuals in rural tribal communities because so many travel to Anchorage. Research products, such as the brochure, were seen as potentially helpful for the members of the general public, both AN and non-Native.

Share Results in Ways that Reach all AN Audiences

Research results should be shared in multiple ways to reach all AN audiences. Additionally, dissemination products should incorporate AN/AI languages and values, contain "flashy" graphics or videos, use large print, and have contact information to solicit more information.

Attendees suggested urban audiences might be easiest to reach on the Alaska Native Tribal Health campus using electronic educational panels located in the lobbies of clinics, home

screens on public computers, and print media like posters, banners, and tri-fold brochures on display in waiting areas. They also suggested posting dissemination materials in waiting areas specific to the project, such as those for primary care or behavioral health services. Overall, attendees wanted to see more fliers in more locations in the clinic. Another suggestion of a convenient way to reach urban audiences was employee picnics and community events in which large numbers of AN/AI people gather.

Attendees wanted to make sure that research results were distributed to residents of rural AN villages. They suggested advertising in major television news or print news that can be seen and heard by village audiences, most notably by elders without computer access. Attendees indicated Anchorage-based print, television, and radio news are often distributed or rebroadcast in rural village communities. Specific venues could be larger in-state newspapers, television, and radio; tribal and village newspapers; or paid media-based advertising. The sentiment of attendees was that earned media (i.e., media coverage not paid for or owned) by non-tribal organizations may not necessarily be the best venue, but that paid advertisements containing tribal news were an acceptable way to capitalize on the reach of these non-tribal media sources. These avenues were seen as acceptable, even on the topic of trauma. Lastly, attendees wanted research activities and results disseminated through electronic sources that can be easily shared, such as social media (Facebook and Twitter) and electronic newsletters. Attendees said they felt that all forms of results (Anchorage Native News articles, handouts, brochures, PowerPoints, peer-reviewed publications, etc.) should be shared on the SCF website.

Provide a Summarized Status Update at Each Stage of the Study

Attendees wanted additional research project summaries like the T-SBIRT PowerPoint. However, they also requested that more information about the number of AN/AI participants who were involved in the development and pilot of the T-SBIRT be more clearly presented. Attendees stated that a summary would suffice for most people and those who wanted more could contact the SCF Research Department to ask questions or to acquire more detailed information. Attendees anticipated that community members would want to know more about the research process and data analysis. Attendees also wanted a summary of all current research activities at SCF.

Second to having information shared in different levels of detail, attendees expected research activities be shared before, during, and after active data collection. All forms of

dissemination were seen as useful, but if budget only accommodated one form of dissemination, attendees preferred to wait until the end of the study or when results prompted changes to the health care system.

Use Results to Improve Care for Trauma and Related Symptoms

Trauma was regarded as having wide-ranging impacts on the AN/AI community. Attendees reported that they felt providers, specifically behavioral health providers and tribal doctors, should know about the results of SCF research projects, because research should enable providers to improve care for people with trauma. Results should be shared with providers to increase communication about trauma and related behavioral health services between providers. SCF and the statewide tribal health organization, the Alaska Native Tribal Health Consortium, were seen as having the funding, resources, and unique responsibility to conduct research to improve health outcomes of AN/AI people and to make these research efforts public.

DISCUSSION

The Alaska Native Health Research Forum format, T-SBIRT presentation, ARS, and discussion groups were well received by Forum attendees. This positive reception is consistent with the preference for transparent communication identified in the SCF community (Avey et al., 2016; Hiratsuka, Brown, Hoeft, & Dillard, 2012; Shaw, Robinson, Starks, Burke, & Dillard, 2013) and with the preference for open-house style events identified in other indigenous populations in the circumpolar north (Pufall et al., 2011).

However, unlike many other community-based dissemination efforts by academic researchers who partnered with AN communities to co-develop culturally relevant formats (Boyer, Mohatt, Pasker, Drew, & McGlone, 2007), Forum feedback suggested that the PowerPoint presented by our staff was a clear and interesting form of dissemination in this tribal health setting. The effectiveness of the PowerPoint presentation may be due, in part, to the forming of the presentation by a group of indigenous researchers specifically for a non-scientific population, limiting the presentation to 15 minutes, not including data tables or graphs in the presentation, the English speaking audience, and the near verbatim script to eliminate non-meaningful utterances. Still, the audience may have also simply responded in a desirable way as the presenter asked the rating questions immediately after the presentation, the audience may

have been comprised of people who possessed a greater interest in research than the community as a whole, or had been exposed to more research studies.

Attendees described ways that owned media (i.e., those controlled by the organization) or tribally controlled news formats were preferred to earned media by national non-AN/AI sources (e.g., *The New York Times*) for disseminating results of tribal research. This preference is consistent with the literature, which indicates that results should be usable by the community involved in the study and that findings should be controlled by tribal organizations maintaining tribal sovereignty of intellectual property, including dissemination products (Harding et al., 2012). Interestingly, although providers at SCF and Elders in rural tribal communities were identified as key audiences, tribal and institutional leadership within SCF were not described as key audiences of the results of the study. However, it is likely that attendees were prompted to focus on the needs of their rural counterparts as the first presentation of the Forum, delivered by a SCF board member, reviewed the research process at SCF and heavily emphasized the oversight provided by tribal and institutional leadership. Similarly, although there were sentiments about the unique responsibility of tribal health organizations to conduct research, there appeared to be a clear lack of distinction between differing tribal entities among many attendees. Again, the first presentation may have played a role in this as it stressed the more recent shift to research conducted by AN people for AN people. Since the Forum, research staff have continued to analyze data and participate in a special SCF quality-improvement workgroup that addresses trauma-related services at SCF. Research staff have begun to draft a final results manuscript to complement a published manuscript on the T-SBIRT development (Hiratsuka et al., 2016).

Research staff also received permission from the SCF Board of Directors and Cherokee Nation IRB to disseminate updated results at two conferences intended to reach AN/AI researchers, clinicians, and health service administrators. The first presentation was a PowerPoint delivered at the Indian Health Services Division of Behavioral Health Conference. These results included additional technical information about the focus groups and interviews and the development of the T-SBIRT, the T-SBIRT process as tested, the usability and acceptability results of the pilot, the sensitivity and specificity of the PC-PTSD, and predictive validity related to quality of life. Audience members expressed satisfaction with the presentation, described it as one of the most data driven of the conference, and wanted to know more about the process so

they could implement similar procedures at their institutions. The second presentation was a round-table discussion with similar talking points but that emphasized the clinical utility of the T-SBIRT. Because of the Alaska Native Health Research Forum, community dissemination efforts are planned for tribal news sources following SCF and CNHS Tribal Leadership approval.

Future Research

Future research should explore differences in dissemination strategies between academic CBPR partnerships and tribally-driven research located within the tribal health setting. Future research may also examine differences in perceptions of trustworthiness between research communicated at an open-house style event and public events in other settings. Research on dissemination efforts in large tribal health service areas may explore the reach of urban media syndication services to rural villages or dissemination to tribal partners, such as the Association of Village Council Presidents. Lastly, although attendees of this Forum preferred to receive overviews of research activities, researchers who produce electronic dissemination products should explore the liberal use of hyperlink references to ongoing and past local efforts, so those who want more information can click to the original sources.

Lessons Learned

Even among organizations, such as SCF, which are committed to conducting research using a CBPR process, the timing of disseminating results can be challenging and remains an area for improvement. For instance, community stakeholders may desire preliminary results; however, in many settings, such as SCF, all research results must first be reviewed by tribal leadership and authorized for distribution to the community. Yet, it remains critical for researchers to be cognizant to provide ongoing communication within each stakeholder group because this is crucial to conducting CBPR. Adequate tracking of tribal approval authorizing dissemination of incremental results, coordinating with external partners, and tailoring research dissemination products requires attention to detail, persistent effort, reporting infrastructure, and considerable reflection of context. In disseminating research results to community stakeholders, researchers may find it helpful to distinguish between research processes, research results, and the use of results to improve care. Distinct from research results and improvements to clinical care, types of research process information appropriate to share with stakeholders may include

newly awarded funding, developed partnerships, or added faculty/researchers. In regards to dissemination, this community sample was interested in hearing about research results first and then the methods and rationale underlying their discovery.

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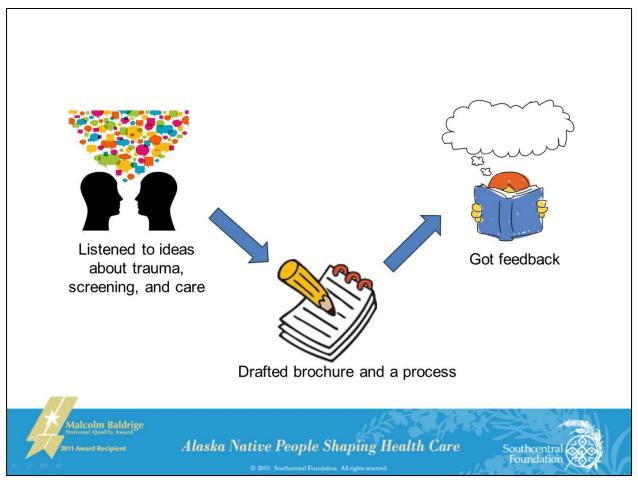
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Figure 1. Example Slide with Presenter Script

Script: "We began the project by first listening to ideas about trauma. We did interviews with providers and focus groups with customer-owners and patients at each of the two sites – a total of 37 people. We listened to ideas about what types of trauma people see in our communities and the barriers to healing from trauma. We then asked for recommendations about whether screening was a good idea, who should ask screening questions, what questions should be asked, and ways to provide care like using brochures. We then used this information to select screening questions, draft a brochure, and create a process for caring for trauma in primary care. We then went back to the same people several times for feedback before we finalized the process."

Figure 2. Intervention Brochure with Presenter Script

Understanding Trauma

What happens after trauma?

If you have witnessed or experienced trauma, you may find yourself reliving events from the past. This is normal.

Sometimes, remembering or reliving events can impact your daily life. If it does or you find yourself thinking of harming yourself or others, there are resources that are immediately available to help you.

Resources Available

24-Hour Careline at 1 (877) 266-4357 (toll-free, Statewide) or text "4help" to 839863

In Anchorage, CrisisLine at (907) 563-3200

Crisis Text Line: Text "CTL" to 741-741 for free emotional support and information 24-hours-a-day

Behavioral Health Services at (907) 729-2500 (option 1 or 2) for same-day access/walk-in appointments.

Contact your Southcentral Foundation (SCF) Primary Care Provider (PCP) at (907) 729-3300 for behavioral health resources or referrals.

Denaa Yeets' Suicide Prevention (907) 729-5260 or toll-free at 1 (800) 478-3343

Attend a Family Matters Night, every Thursday evening from 5:30-7:30 p.m. with a variety of learning circles available.

Anchorage Police Crisis Intervention Team (CIT) Officer at (907) 786-8900

Behavioral Services Division
(907) 729-2500
Anchorage, Alaska
www.southcentralfoundation.com

Southcentral Foundation

What is trauma?

Everyone responds to distressing events differently.

Trauma is a deeply distressing or disturbing experience that can be unusually frightening or upsetting. Events such as a serious accident, medical conditions, natural disaster, loss of a loved one, violence, neglect, abuse, or being in a combat/war zone can be traumatic.

We all experience ups and downs in our lives, and that is normal. Sometimes though, the reactions are so intense we may have a hard time dealing with them.

What are common reactions to trauma?

- Stopping healthy, routine activities.
- Feeling tired, irritable or angry.
- Bodily pain, stomach upset, or frequent headaches.
- Crying more than usual.
- Changes in sleeping or eating patterns.
- Withdrawing or pushing people away.
- Having bad memories or dreams about the event.
- Thoughts of hurting yourself or others.
- Feeling anxious, worried, jumpy or afraid.
- Feeling numb.
- Feeling ashamed or guilty.
- Finding it hard to stay focused.
- Questioning one's own faith or spiritual beliefs.
- Using unhealthy coping skills such as drinking, drugs, gambling or overeating.

Steps to achieving wellness

- Reaching out for help is healthy. Find someone you trust and share as much of your story as you feel comfortable.
- If you get "stuck" review resources available and talk to a health care provider.
- Honor your culture and celebrate your strengths.
- Take care of yourself! Eat healthy, drink water, exercise and get enough sleep.
- Get in a healthy routine.
- Stay connected with family and friends.
- Be patient. Healing takes time.
- Be kind to yourself. Don't blame yourself or dwell on ways you could have prevented the event from happening.

Script: "Aside from selecting questions to ask, we developed a brochure to be used by providers to talk about trauma. A version of the flyer is in your packet. It is green and labeled 'Understanding Trauma.' It's actually a second version of the brochure created after the project ended for use in the clinics. Opening it, you can see that the brochure covers, What is

trauma? What happens after trauma? What are the common reactions to trauma? Steps to achieving wellness as well as resources available. This brochure was based on ideas from the focus groups and interviews. The feedback we got was that conversations about trauma needed to normalize trauma since [sic] trauma is something that happens to most people in their lifetime. We also got feedback to keep it simple considering that it will be delivered in a primary care clinic. In terms of content, it was important that it have information about positive coping, things that people can do, social support, and resources. This would allow providers to better assess coping and social support of those they serve. Lastly, it was important that the brochure be used as part of establishing a respectful, trusting, and safe relationships between providers and customer-owners. Trust and safety are very important for those who have experienced trauma."

DISSEMINATING THE RESULTS OF A DEPRESSION MANAGEMENT STUDY IN AN URBAN ALASKA NATIVE HEALTH CARE SYSTEM

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Abstract: Increased attention to diagnostic accuracy in depression screening and management within primary care has demonstrated inadequate care when patients prematurely discontinue recommended treatments such as medication and counseling. Decision-support tools can enhance the medical decision-making process. In 2010, the Southcentral Foundation (SCF) Research Department developed a stakeholder-driven decision support tool to aid in depression management. This paper describes feedback from attendees at SCF's 2016 Alaska Native Health Research Forum (Forum) regarding a dissemination product highlighting the aforementioned study. Forum attendees participated in a small group discussion and responded to a brief survey using the audience response system. Thematic analysis was conducted on data from the small group discussion. Overall, Forum attendees responded favorably to the dissemination product. Most agreed the presentation was clear, the amount of information presented was appropriate, and that results were presented in an interesting way. Small group discussion participants provided constructive feedback about why depression-related research results should be shared; how they believed results should be best shared; who results should be shared with; when and where results should be shared; and what level of research results should be shared. The stigma associated with depression treatment may be assuaged if results are shared in a way that normalizes support for depression treatment. Community member involvement in disseminating results has potential to make information more acceptable and meaningful.

The purpose of this pilot project was to determine if a co-developed depression management tool improved depression management, health care decisions, and health outcomes in Alaska Native and American Indian individuals who received services at Southcentral Foundation's (SCF) primary care center. The current article describes the pilot project and the feedback from attendees at SCF's 2016 Alaska Native Health Research Forum regarding a dissemination product highlighting the study.

INTRODUCTION

Behavioral health disorders in primary care are prevalent and potentially costly to patients and the health care system (Goldman, Wise, & Brody,1998; Greenberg, Fournier, Sisitsky, Pike, & Kessler, 2015; Kaufman, Beals, Croy, Jiang, & Novins, 2013; Kurian, Grannemann, & Trivedi, 2012; Miranda, Hohmann, Attkisson, & Larson, 1994; Ormel et al., 1994), yet these disorders are often under-recognized and, accordingly, untreated (Mulrow et al., 1995; Swartz & Rollman, 2003; Williams, Kerber, Mulrow, Medina, & Aguilar, 1995). Limited evidence indicates that depression is at least as common (if not more common) among AN/AI people than the general US population (Duran et al., 2004). Nationally, only half the people who meet the criteria for a depressive disorder are ever treated, resulting in unnecessary suffering and financial cost to affected individuals, their families, employers, and the health care system (Berardi et al., 2005; Broadhead, Blazer, George, & Tse, 1990; Duncan, Best, & Hagen, 2010; Greenberg et al., 2015). Over the past two decades, increased attention to depression screening diagnostic accuracy and management within primary care has demonstrated less than optimal care, with patients prematurely discontinuing recommended treatments, such as medication and counseling. One-third of patients discontinue treatment within 1 month and one-half within 3 months (Almanzar et al., 2014; Frank, Huskamp, & Pincus, 2003; Seelig & Katon, 2008).

Historically, clinical practice guidelines have been designed to provide the best evidence for health care professionals' decisions about patient health care, not necessarily for advancing patient involvement in the decision-making process. These one-for-all practice guidelines and recommended management strategies thus do not take into account the differences in conceptualizing causes, treatment preferences, and medical needs of the individual or community, suggesting a demand for more flexible guidelines and accompanying decision-support tools that facilitate patient involvement in clinical decision making (Barry & Edgman-Levitan, 2012; Eddy, 1991; Gilmore, 1993; Krahn & Naglie, 2008; Mahone et al., 2011; McCormack & Loewen, 2007; Mistler & Drake, 2008; Nease & Owens, 1994). Clinicians have been working towards more patient-centered approaches to developing clinical practice guidelines and are engaging stakeholders in that process (Bennett et al., 2017; MacLennan et al., 2017). Decision-support tools offer providers and patients an expedient method of sharing knowledge and individualized health care information to help make decisions around health care. Decision-support tools can enhance the medical decision-making process; improve patient-

provider communication; inform options for treatment; provide a balanced, value-neutral presentation of the advantages and disadvantages of each option; and help patients clarify their preferences and values about treatment. These processes support patient involvement and participation in achieving ownership of their treatment and well-being.

Evolution of Depression Management at Southcentral Foundation

In 2001, SCF's Anchorage Native Primary Care Center (ANPCC) collaborated with SCF's Behavioral Services Division to increase access to behavioral health-related services for AN/AI people (Dillard & Christopher, 2007). Through this effort, an annual depression screening using the nine-item Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer, & Williams, 2001) was implemented within SCF's ANPCC (Dillard & Christopher, 2007). Although the implementation of depression screening identified more individuals with depression seen at the ANPCC that had not previously been diagnosed, the loss to lack of follow-up when patients were referred to specialty behavioral health services (i.e., individualized therapy, group counseling) remained high. In 2003, SCF initiated another improvement effort to better integrate behavioral health services in the ANPCC by creating a behavioral health consultant position on each integrated care team; however, gaps in screening and treatment still remained (Driscoll et al., 2013). The two areas for improvement related to depression management that remained were: 1) some individuals chose not to fill or refill their antidepressant prescriptions, and 2) few individuals referred by primary care providers to a behavioral health provider ever completed the referral and had a behavioral health-related visit (Dillard & Christopher, 2007). The SCF Research Department subsequently approached clinical, administrative, and tribal leadership about engaging stakeholders to develop a decision-support tool to facilitate discussions between providers and patients who screened positive for depression on the PHQ-9. The SCF Research Department hypothesized that the reason patients were not filling prescriptions or following through with referrals was because they were not ready to choose an intervention, or recommendations from providers were not in line with patient values and preferences. Their solution was to create a stakeholder-driven depression management decision support tool that took these factors into consideration and could conceivably measure a reduction in the number of unfilled prescriptions or unfulfilled referrals to behavioral health. These discussions resulted in the submission of a pilot project proposal to the Patient Centered

Oriented Research Institute (PCORI). In 2010, the SCF Research Department received funding from PCORI to involve community members in a collaborative research study to develop a stakeholder-driven decision support tool to aid patients, providers, health care administrators, and tribal leaders to improve depression management at SCF. In 2013, PCORI provided additional funds to SCF through an Engagement Award Initiative Notice (EAIN) to augment disseminating research results to patients and providers. This paper describes a Depression Management Decision Support Tool (DM-DST) with particular emphasis on a product called a "rack card," a two-sided, half-page handout placed in exam rooms and clinic lobbies in display racks, which was shared with SCF's Alaska Native Health Research Forum (Forum) attendees.

Background

The "Engaging Stakeholders to Improve Depression Management in a Tribal Health System" pilot project was designed to determine if a co-developed depression management tool improved depression management, health care decisions, and health outcomes in AN/AI individuals who received services at the SCF ANPCC. The aims of the study were to: 1) identify SCF leader, provider, and patient priorities or needs that influence depression management decisions in AN/AI individuals who receive services at the ANPCC; 2) develop a decision-support tool to help translate and integrate SCF leader, provider, and patient priorities or needs into depression management decisions; 3) evaluate the effectiveness and cultural appropriateness of the decision-support tool for AN/AI individuals who receive services at the ANPCC; and 4) determine if the decision-support tool improves depression management, health, and economic outcomes.

Semi-structured interviews and focus groups were used to obtain feedback from SCF patients, providers, and leaders on concerns and preferences for depression management and treatment. Results from this process were subsequently used to develop an iPad-based DM-DST, a patient-centered tool designed to translate preferences for depression management and evidence-based care into practice at SCF (Starks, Shaw, Hiratsuka, Dillard, & Robinson, 2014). Results suggested that discussions about depression treatment should begin by normalizing depression and acknowledging individual patient's life events. Patients preferred having a tool that: 1) facilitated shared terminology to simplify treatment discussions with providers, 2)

allowed the opportunity to describe their personal views about the causes of their depression, and 3) communicated depression management preferences with their provider (Starks et al., 2014).

With these preferences in mind, the DM-DST was developed and pre-tested with 20 patients with depression symptomology and five providers. The DM-DST was subsequently revised with data collected during the pre-test and feedback from an 11-member project steering committee consisting of individuals from the SCF research and data services staff, SCF primary care and behavioral services leadership, information technology leadership, and a national expert in AN/AI behavioral health. After revisions, the DM-DST was piloted with a larger sample of patients using a randomized cluster design. The intervention group consisted of 131 AN/AI adults who screened positive for depression and agreed to participate. Of these, three withdrew after the DM-DST malfunctioned, one withdrew because of fatigue, one did not consent to electronic health records review, and 14 were excluded from analyses because they were determined to be ineligible after the study had begun. The resulting intervention group consisted of 112 participants (88 women) with mean (SD) age of 40.7 ($SD = 16.2$) years. Nearly three quarters (74%) were unmarried and had a median annual income of $50,000 to $59,000. The control group consisted of the 263 AN/AI adults who screened positive for depression in the treatment-as-usual condition during the same period. Demographic information about control participants was not calculated. The total sample size for the pilot was 375 individuals.

Pilot Study Results Summary

Pilot results suggest that the DM-DST helped providers and leaders enhance their understanding of the subjective experiences and depression management preferences of patients with depression within SCF's health system. Patients who used the DM-DST were more likely to select physical and emotional symptoms of depression than cognitive ones. They were most interested in pursuing counseling and medication management and were least interested in peer-support groups, herbal remedies, and spirituality. They were also generally supportive of, but undecided about, stress reduction training and education on healthy eating.

Implementation Guidance and Results Dissemination Before the Alaska Native Health Research Forum

After the pilot study, the SCF Research Department received a PCORI EAIN award to disseminate pilot study results and examine implementation of services informed by the study

results. The project steering committee reviewed the results of the study and requested guidance on disseminating and implementing the results of the DM-DST. The steering committee also recommended that materials discern between informative and actionable results to help implement the DM-DST. Dissemination activities were tailored to reach specific stakeholder groups: the SCF quality improvement committees, six primary care clinics, obstetrics/gynecology providers, pediatrics providers, certified medical assistant supervisors, and patients. SCF leaders and different health care providers then reviewed information about the pilot study and provided guidance about how best to implement the use of the DM-DST within primary care, as well as how to disseminate information to both health care providers and patients. Depression treatment preference and symptom information collected in the pilot provided practical advice about depression management and patient needs to tribal leadership and health care providers. Engaging patients and other stakeholders helped shape plans for using the DM-DST in primary care clinics and to establish project result dissemination plans. As expressed in these plans, study staff worked with the SCF Public Relations Department to create a toolkit to disseminate pilot summary results to patients and the health care system. A multi-tiered approach was used to share study information, which included:

- An article in SCF's quarterly community newspaper (*Anchorage Native News*);
- An article in SCF's weekly, internal electronic newsletter (*SCF Communicator*);
- Print infographic of select pilot study results shared with SCF providers;
- SCF Facebook post that highlighted the pilot study results; and
- The display of a rack card (promotional brochure) that highlighted select study results, in exam rooms and clinic lobbies.

Although various materials were generated to share results of the project, only one product was highlighted at the Forum. SCF Research Department staff worked with the SCF Public Relations Department to create a promotional rack card (see Figure 1) as a method of sharing results of the pilot study. Rack cards are often used in marketing to display information, are typically 4" x 9," and may contain information on one or both sides. Rack cards are usually found in business or medical offices and are typically located in waiting areas or other high traffic areas. More often, rack cards are used in the tourism industry in hotels, airports, or visitor centers to promote tours and attractions for visitors. They are designed to visually attract a person's attention and are typically printed on glossy, colorful, high quality card stock that

contains images. The rack card was selected by an SCF Research Department workgroup to highlight during the Forum as a new method of disseminating results, and the Forum provided an opportunity to obtain patient feedback on this method.

PowerPoint Presentation

The Forum PowerPoint presentation consisted of 10 slides and a 12-minute oral presentation about the development of the DM-DST and pilot study results. The presentation began with a brief five-minute background about the study purpose and rack card design, followed by a 15-minute small group discussion. After the small group discussion, attendees responded to three questions using the Audience Response System (ARS) to determine whether the information on the rack card was clear, accurate, and interesting. (The ARS is described elsewhere in this special issue; see Hiratsuka et al., 2018, "Approach and Methods"). The presenter devoted 10 minutes informing attendees about the study, including the overall goal of the study, methodology for the different aims of the study, and lessons learned from each aim of the study.

RESULTS

Data Analysis

Detailed information about data analysis methodology can be found elsewhere in this special issue (see Hiratsuka et al., 2018, "Approach and Methods"). Qualitative themes were coded by each of the primary discussion questions: *Why should results be shared? How should results be shared? Who should hear about the results? What results should be shared? Where should results be shared? When should results be shared?*

Audience Response System Results

After the background presentation about the purposes of the rack card and study, Forum attendees responded to three questions about the rack card (Table 1). Overall, Forum attendees responded favorably. Most of the respondents (78%) agreed that the presentation was clear. Even more (85%) agreed that the amount of information presented was about right. More than three-quarters (77%) agreed that the results were presented in an interesting way.

Table 1
Participant's Evaluation of the Rack Card Publicizing the Depression Management Tool

Survey Response	N	%
The presentation about the results was clear.	28	100
Strongly disagree	0	0
Disagree	6	22
Agree	13	46
Strongly agree	9	32
The amount of information was about right.	27	100
Strongly disagree	0	0
Disagree	4	15
Agree	17	63
Strongly agree	6	22
The results were presented in an interesting way.	30	100
Strongly disagree	1	3
Disagree	6	20
Agree	14	47
Strongly agree	9	30

Small Discussion Group Results

Why Should Results be Shared?

Participants in each group suggested that sharing results could help normalize depression by making it okay to talk more openly about it. Some mentioned that many people suffer from depression, and people may participate in research studies on depression if they see results have been shared. Another said that sharing the information "helps so others experiencing depression [can] relate and help them feel more open to seeking help." Participants were also asked to consider why results should be shared using a rack card format. Participants highlighted the rack card's inclusion of treatment and prevention options. People liked seeing different categories of depression treatment options in the rack card, and some stated that they may not have realized that options were available or useful for depression management, such as stress management or traditional healing. Others thought the rack card could be a good way to share information about resources with friends or family members as they could easily take the rack card home. One person mentioned that some people do not necessarily like participating in small discussion groups, such as the discussion they were participating in at the Forum, so they would likely prefer written results like the rack card.

How Should Results be Shared?

Many participants had suggestions for improving how results could be disseminated. Some participants reported that they felt the rack card contained the right amount of information;

others wanted more information; still others felt there was too much information. The title of the rack card, "Depression iPad Application Study" was confusing to some. One person mentioned that they thought the rack card did not apply to them because they do not have an iPad. Attendees suggested that the title be changed to "Depression Management Study" as the study was more about depression management than iPads. The small groups also discussed formatting. Several groups commented that the text was too small and difficult to read, particularly for elders. Participants suggested the use of a tri-fold brochure format, so text can be made larger and more information can be included in the brochure. Some people liked the rack card format and referred to it as "catchy," "trendy," "colorful," and "bright." The small groups specifically discussed the brochure's infographics, which were the pictures that corresponded to the data categories on the charts. For example, on the treatment preferences graph, printed beside the "exercise" treatment preference category there is an icon of someone running. Some infographics were well received, but others were not. Rather than using the image of an iPad, attendees suggested using an image of a person. Participants also recommended that results be framed in a more positive way by emphasizing what helped people with depression. A suggestion was made to provide an explanation about how to read graphs depicted in the rack card, as not everyone is familiar with interpreting data in graph-format. Some people suggested including contact information for SCF behavioral health-related services, such as behavioral health consultants and learning circles (group therapy) in addition to the study results. The groups also discussed methods of sharing information, other than the rack card. People mentioned disseminating results using social media (e.g., Facebook), local radio talk shows, and presentations like the Forum.

Who Should Hear About the Results?

All groups recommended that the results, in general, be shared with patients. Some suggested they be shared specifically with people who receive behavioral-health-related services. One group stated that more studies about depression need to occur in rural Alaska. Some recommended sharing study results with the local Elder's program and another with youth. Participants also suggested that the rack card specifically be shared with family members of people with depression and providers so that family members and providers understand the preferences for depression treatment that people in the study shared.

When Should Results be Shared?

Overwhelmingly people suggested that results for depression studies should be shared on an ongoing basis: before data collection, during data collection, and after the research is done. Participants did not specifically discuss when to share results using the rack cards.

What Results Should be Shared?

Although some participants thought only key points about the depression study should be shared, many also wanted more nuanced detail. For example, some said more information about the methods for obtaining the results, the length of the project, and more context about the study, particularly the link between the iPad application and depression, should be included in the rack card. Some attendees wanted additional background about who was doing the research included in the brochure. Participants said that because SCF has a good reputation for research, the rack card should emphasize that the study results came from a credible source and that credibility should be highlighted in all results made available through SCF. Participants also liked seeing, in the rack card, the percentages of research participants in the study who used SCF services; one person suggested that the percentages be a different color to help them "pop" rather than blending in with the rest of the rack card. Another reason mentioned for using the rack card was that it could be helpful to people who are experiencing depression and are not ready to talk about it with others. The rack card could potentially inform people to become more ready to discuss depression with family, friends, or providers, without having to interact with someone in person to receive the initial information.

Where Should Results be Shared?

One suggestion was to place rack cards in the lobby at the ANPCC to make them more accessible to patients. Suggestions for other locations to disseminate the rack cards across the Alaska Native Medical Center campus included locations easily accessible to patients such as the cafeteria, pharmacies, by the front entrance to clinics, in clinic exam rooms, and at clinic front desks.

Participants also discussed how results about depression studies in general should be shared. One group recommended using television screens in clinic lobbies, also known as passive education panels, to share all of the SCF Research Department's study results, not just for this study, as reporting on one study would get repetitive. Discussion groups also acknowledged that some people do better hearing and seeing results rather than just reading them

in print. Others suggested that results be shared in print in the SCF community newspaper, the *Anchorage Native News,* or the regional newspaper, the *Frontiersman*. Several participants suggested that depression-related results be shared with youth at both schools and programs in the community. Other public community locations were also proposed, such as homeless shelters, bus stations, public libraries, youth-serving agencies (i.e., Boys and Girls Club), and bulletin boards around town, airports, and coffee shops. There were also suggestions that the results be shared at special community events like the annual Alaska statewide conference of the Alaska Federation of Natives, the annual Anchorage-based SCF Gathering, and various SCF sponsored patient walk/run events.

DISCUSSION

Feedback provided by Forum participants is useful to consider for results dissemination in general, but also for disseminating results specifically concerning depression. Screening regularly for depression in primary care, similar to routine blood pressure or cholesterol screenings, has been suggested as a way to destigmatize and normalize depression (Starks et al., 2014). Forum attendees also commented that normalizing depression symptoms and treatment options could reduce any stigma associated with seeking depression treatment. Some attendees suggested that seeing the high percentages of specific symptoms of depression (i.e., loss or gain of sleep) was something they could relate to and make them feel less alone. The value of knowledge-sharing through local initiatives similar to this one has the potential to decrease stigma about depression and other behavioral health conditions, by showing people that others may have similar experiences, thus breaking down stereotypes (Byrne, 2000).

The formatting and extent of information included in dissemination materials, such as rack cards, should be considered carefully. In a review concerning formatting, Versloot et al. (2015) suggest that the more vivid, intuitive, and visual a document is, the more likely it will be read, remembered, and used. Although many discussion group members found the rack cards to be interesting and visually stimulating, some brought up the importance of creating dissemination materials that can easily be seen by anyone, with a special mention for elders or others who may have poor vision. This suggestion highlights the notion that using multiple channels for disseminating results is essential to expand the reach to accommodate various recipients. Participants provided guidance on where to disseminate research results, including the

Alaska Native Medical Center campus and the larger Anchorage community. Sharing results outside of SCF using a rack card format has potential challenges. In particular, contextual factors familiar to patients and SCF staff may not be readily apparent to a broader audience and may require more description and background than a rack card offers. Contextual factors may be partially addressed through disseminating research results using a variety of methods. Participants suggested other ways of sharing the results of the depression management study that benefit different methods of delivery, including face-to-face (i.e., presentations), social media (i.e., Facebook), and audio (i.e., radio talk show).

Community member involvement in disseminating results has potential to make information more acceptable and meaningful, especially in AN/AI communities (McShane, Smylie, Hastings, & Martin, 2006; Rivkin et al., 2013; Smylie, Kaplan-Myrth, & McShane, 2009). During the Forum, attendees were asked to suggest who in the community should receive study results. Most participants suggested that patients in general and behavioral health providers be given the results. Some recommended that results be shared specifically with youth and elders. In one research project that examined disseminating results in an Inuit community, community members suggested integrating dissemination strategies with existing information sources, which included elder's advice (McShane et al., 2006). Incorporating research information dissemination into pre-existing local approaches can help ensure that results are shared in a way that reaches more community members (McDonald et al., 2016).

Opportunities for Improvement

Although the Forum provided meaningful insight, some limitations are worth noting. There were only 31 attendees at the forum, and only 29 participated in the discussion groups; therefore, results shared in this study should not be viewed as representative of all SCF patients. Furthermore, as most attendees were women over 40 years old, there was limited information about male preferences. The same can also be said regarding younger participants: only one-third of participants were less than 40 years old. Younger people may have other perspectives on sharing results related to depression management. Although the presenter prefaced the ARS questions by asking attendees to focus their response only on their reaction to the rack cards, some also responded to content about the study purpose and rack card introduction that was shared during the oral presentation prior to the discussion groups.

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Figure 1. Rack Card Shared with Alaska Native Health Research Forum Attendees

COMMUNITY DISSEMINATION IN A TRIBAL HEALTH SETTING: A PHARMACOGENETICS CASE STUDY

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Abstract: Alaska Native and American Indian (AN/AI) people experience a disproportionate burden of health disparities in the United States. Including AN/AI people in pharmacogenetic research offers an avenue to address these health disparities, however the dissemination of pharmacogenetic research results in the community context can be a challenging task. In this paper, we describe a case-study that explores the preferences of AN/AI community members regarding pharmacogenetic research results dissemination. Results were presented as a PowerPoint presentation at the 2016 Alaska Native Health Research Forum (Forum). An audience response system and discussion groups were used to gather feedback from participants. Descriptive statistics were used to assess attendee understanding of the presentation content. Thematic analysis was used to analyze discussion group data. Forum attendees needed time to work through the concept of pharmacogenetics and looked for ways pharmacogenetics could apply to their daily life. Attendees found pharmacogenetics interesting, but wanted a simple description of pharmacogenetics. Community members were optimistic about the potential benefit pharmacogenetic medicine could have in the delivery of health care and expressed excitement this research was taking place. Researchers were urged to communicate throughout the study, not just end research results, to the community. Furthermore, attendees insisted their providers stay informed of research results that may have an impact on health care delivery. Conversational forms of dissemination are recommended when disseminating pharmacogenetic research results at the community level.

The purpose of this case study was to explore the preferences of Alaska Native and American Indian community members regarding pharmacogenetic research results dissemination. The current article first describes the case study and then the feedback from attendees at Southcentral Foundation's 2016 Alaska Native Health Research Forum regarding the presentation of the information.

INTRODUCTION

Alaska Native and American Indian (AN/AI) people shoulder a disproportionate burden of health disparities in the U.S. Despite many efforts to close the health gap between the general U.S. population and the AN/AI population, health disparities remain (Cobb, Espey, & King, 2014; Espey et al., 2014; Roubideaux, 2002). Health gaps are a result of many complex factors, including genetic differences that contribute to individual variation in response to provider-recommended medical interventions and published guidelines (Zhang & Dolan, 2008). Genomic medicine offers an avenue to close a portion of this gap (Zhang & Dolan, 2008) through tailored and/ or targeted interventions based on genetic variation.

The goal of pharmacogenetic research is to develop laboratory tests and screenings that can be used to personalize therapy and improve individual patient and population health outcomes (Fohner et al., 2013; Lesko & Schmidt, 2012). Pharmacogenetic research seeks to identify genetic contributors to inter-individual variability in drug metabolism, disposition, and response (Lesko & Schmidt, 2012). Genetic variation contributes to differences in response to certain medications (e.g., warfarin, tamoxifen, tacrolimus) among specific populations (European American, Asian American, and African American); however, biomedical research and usable information are not available for all populations (Whirl-Carrillo et al., 2012). Current pharmacogenetic tests are based off of genetic differences and/or environmental gene-modifying factors found in the general population, and these differences may not be present and/ or applicable to AN/AI populations.

Racially and ethnically diverse groups are consistently underrepresented in biomedical research (Buchwald et al., 2006; Hiratsuka, Brown, Hoeft, & Dillard, 2012). This could, in part, be due to the history of research misconduct that has taken place in AN/AI communities (Foulks, 1989; Harmon, 2010). In recent years, community engaged partnerships have been developed to re-establish trust with AN/AI communities and provide opportunities to participate in biomedical research (James et al., 2014; Boyer et al., 2011; Woodahl et al., 2014). Community engaged research methods have been an effective strategy to engage AN/AI people in pharmacogenetic research.

Community-based participatory research (CBPR) methods provide a robust basis to identify community communication preferences, knowledge, and practice gaps related to research with and for the AN/AI community. A key aspect of CBPR methodology is the

dissemination of findings to all partners including: community, academic, and clinical partners. (Israel, Schulz, Parker, & Becker, 1998). Dissemination of CBPR results to the broader participating community does occur; however, challenges to timely and widespread dissemination efforts have been identified (Chen, Diaz, Lucas, & Rosenthal, 2010; Caldwell, Reyes, Rowe, Weinert, & Israel, 2015; Dillard, Caindec, Dirks, & Hiratsuka, 2018).

Southcentral Foundation Health Care Delivery

In 1998, Southcentral Foundation (SCF) took responsibility for primary health care service delivery to AN/AI people in southcentral Alaska from the federal-managed entity, the Indian Health Service. AN/AI patients are no longer considered "beneficiaries" or "patients" by the SCF health care system, but instead are recognized as "customer-owners" since the AN/AI community are customers of the tribally-owned and operated health care system (Gottlieb, 2013). SCF redesigned the health care delivery method and incorporated an approach focusing on long-term, trusting, consistent provider and customer-owner relationships (Eby, 2007).

CASE STUDY

The Northwest-Alaska Pharmacogenomics Research Network (NWA-PGRN) is a pharmacogenetic research partnership with sites in Alaska, Washington, and Montana. This network seeks to develop pharmacogenetic research infrastructure through community and academic partnerships to foster and support inclusion of AN/AI populations in pharmacogenetics research (Boyer et al., 2011; Woodahl et al., 2014). SCF is one of eight NWA-PGRN partners. NWA-PGRN aims to understand key environmental, clinical, and disease modifiers in the context of underlying genetic variation and disease management. However, how these results would be disseminated, accepted, and used by the community is equally important to the research (Boyer et al., 2011). An initial research study of the NWA-PGRN at SCF was to explore broadly the interest of SCF customer-owners in the use of pharmacogenetic tests and their interest in participating in population-based pharmacogenetic research studies. SCF researchers conducted focus groups with pertinent stakeholders (i.e., customer-owners and providers) to identify risks and benefits of pharmacogenetic testing at SCF and for the AN/AI community. Identified risks include issues around confidentiality, health care costs, rationing of health care

services, and stigma based on the results for the individual and the AN/AI community. Benefits identified include decreased health care costs, improved health outcomes, and capacity development (Shaw, Robinson, Starks, Burke, & Dillard, 2013).

A second NWA-PGRN pharmacogenetic research study was to identify and characterize potential clinically significant variations in specific genes thought to account for variability in warfarin, tacrolimus, and tamoxifen metabolism, serum levels, and clinical response (Fohner et al., 2013). Gene variants found in the Confederated Salish and Kootenai Tribes—a site working in collaboration with Montana State University, one of the eight partner sites of NWA-PGRN— differed from all other studied populations, showing extrapolation from other population data are not appropriate and highlighting the necessity of carrying out pharmacogenomics research in AN/AI populations (Fohner et al., 2013). Two relatively novel, and potentially function-disrupting gene differences were also identified, which predict that a large proportion of AN/AI people will have decreased activity in certain genes (Fohner et al., 2015). These genetic variations found in the study population of this pharmacogenetic study were shared with participants in the study, via a one-page descriptive results flyer (Figure 1).

METHODS

SCF hosted the Alaska Native Health Research Forum, a 3.5-hour gathering. A total of 31 AN/AI adults attended the Forum. Quantitative feedback was collected by an Audience Response System (ARS). (The ARS is described elsewhere in this special issue; see Hiratsuka et al., 2018, "Approach and Methods"). Discussion groups were conducted to gather illustrative narrative. A thematic network approach was used to identify common views across the discussion groups (see Hiratsuka et al., 2018, "Approach and Methods"). A detailed description of attendee recruitment, data collection, and data analysis are described elsewhere in this issue (see Hiratsuka et al., 2018, "Approach and Methods").

PowerPoint Presentation

The NWA-PGRN at SCF presentation was conducted in a modified IGNITE presentation format (O'Reilly, 2015). Unlike a traditional IGNITE presentation, in which the presentation is given within 5 minutes and uses precisely 20 slides with each slide advancing automatically after

15 seconds, the NWA-PGRN presentation consisted of a PowerPoint presentation of 10 slides delivered in 15 minutes that were advanced by the speaker (J. Beans). The terms "pharmacogenetics," "DNA," and "genes" were defined. Pharmaceutical drugs were referred to as "medicine" or "medication" to aid in attendee understanding. The layout of the slides varied from one bullet point with a large graphic to a graphic with slightly more written description, and the last slide that had more bullet points and a small graphic. A DNA double helix graphic was on three slides throughout the presentation. Once defined, DNA was referred to as "genes" and the use of the term "genetic" was limited during the presentation. First, the topic of the presentation and the presenter were introduced followed by a detailed description of pharmacogenetics. The next few slides discussed why pharmacogenetic research was being carried out at SCF. How pharmacogenetics research could aid SCF providers in prescribing more effective medications based on a lab test was described. Next, four examples of completed and current pharmacogenetic studies at SCF were presented. Lastly, an example of next steps in pharmacogenetics research at SCF was presented.

Handout

A single page handout (Figure 1) was provided to all attendees in a folder with other forum materials before the presentation.

RESULTS

Quantitative Results

When reflecting on the modified IGNITE pharmacogenetics presentation, most attendees agreed or strongly agreed that the results were clear (79%), the right amount of information was presented (67%), the results were presented in an interesting way (90%), and there was enough background information to understand the research (74%; see Table 1). There was disagreement, however, on the amount of information presented, with one-third (32%) of attendees either disagreeing or strongly disagreeing to the statement, "The amount of information was about right." Eight attendees (26%) disagreed or strongly disagreed to the statement, "There was enough background information to understand the research results."

Table 1
Post Presentation Survey Results

Survey Results	N	%
The presentation about the results was clear.		
Strongly disagree	2	6.9
Disagree	4	13.8
Agree	18	62.1
Strongly agree	5	17.2
The amount of information was about right.		
Strongly disagree	2	6.5
Disagree	8	25.8
Agree	12	38.7
Strongly agree	9	29.0
The results were presented in an interesting way.		
Strongly disagree	1	3.3
Disagree	2	6.7
Agree	15	50.0
Strongly agree	12	40.
There was enough background information to understand the research results.		
Strongly disagree	4	12.9
Disagree	4	12.9
Agree	14	45.2
Strongly agree	9	29.0

Qualitative Results

Overall, the presentation was well received by the forum attendees. Although questions were asked in the order of the question guide (Table 2), attendee responses were broad. Analysis of the discussion groups revealed three themes: 1) grounding the pharmacogenetic concept, 2) importance of pharmacogenetic research occurring in this community, and 3) constant communication throughout research project.

Grounding the Pharmacogenetic Concept

Pharmacogenetics was a new concept for most attendees. Many attendees were unclear about the pharmacogenetic concept and entered in discussion by developing their understanding of the topic, and many attendees grasped at ideas mentioned during the PowerPoint to which they could relate. Some attendees shared experiences of adverse side effects with, and observations of, various medications mentioned in the presentation, including warfarin, Chantix®, amitriptyline, and Lyrica®. As the attendees began to gain clarity on the topic of pharmacogenetics research, one attendee asked, "Are they good genes? Bad genes? How does this affect me?" A number of attendees looked for ways to relate the notion of pharmacogenetics

to their personal situations: "I'm Choctaw. Are the genes different for each tribe? How do we find out our genes?"

The discussion groups provided attendees the opportunity to clarify their understanding of pharmacogenetic research. As the attendees understanding of pharmacogenetics increased, they began to ask specific detailed questions during the discussion groups, like "How did they come up with the goofy names of the genes?" One attendee asked, "Would grandma know what this means?", expressing concern for understanding among older AN/AI community members. The DNA helix image on the handout was described as too complicated and uninviting. "It looks like molecules. I would just put the paper down." One attendee suggested the graphics be simplified and detailed explanations be added so the information could be understood by all. An attendee suggested using animation and humor to keep it up beat when disseminating research results to the community. Multiple attendees found the content uninviting and unfamiliar. Some attendees commented on how the graphics and information about genes needed to be simplified. When looking at a picture of a DNA helix, one attendee commented, "My brain turns off when I see this."

Importance of Pharmacogenetic Research in this Community

Attendees recognized the importance of pharmacogenetic research and said they were encouraged this type of research was being done on the SCF campus. Many attendees described their discontent with trying to find the right dose of certain medications and found relief in the possibility that future customer-owners may not have to experience the same frustration. One attendee said it took them three years to find the right medication that works, and thought medication should not be "one size fits all," referencing a point made in the presentation. Another attendee encouraged pharmacogenetic research at SCF so in the future they would not feel "guinea-pigged" when being subject to the trial and error in finding the correct medication dose. "I feel guinea-pigged when I have to keep trying different medications and dosages. I've had to have my blood levels tested for certain medications." Many attendees summarized points provided by the presentation and handout and agreed it was important pharmacogenetic research took place on the SCF campus so the results could improve health care delivery.

Constant Communication throughout Research Project

Attendees clearly expressed the importance of keeping lines of communication open throughout the entire study. Not only did attendees find importance in communicating

pharmacogenetic research results to the community but encouraged communicating updates of the study's progress and findings before, during, and after initiation of the research project. One individual asserted, "Don't wait until study is completed [to share results]." Broad modes of dissemination were suggested, including local and statewide newspapers, social media, waiting areas in the primary care clinic, pharmacy waiting area, adding a chapter to a text book, pharmaceutical companies, and the National Institutes of Health. Knowledge of pharmacogenetic studies taking place on the SCF campus and the results of pharmacogenetic studies was seen as a mode to engage the community and provide a form of "checks and balances" on the conduct of research taking place in the community.

All discussion groups encouraged providing regular updates to SCF providers on pharmacogenetic research taking place at SCF. Pharmacogenetic research results were seen as potentially having a positive impact on health care delivery at SCF, and most attendees urged that their providers stay informed of pharmacogenetic research results. One participant emphasized the need for SCF pharmacogenetic research results to be communicated to providers by describing the importance of providers to knowing the individual customer-owner's genetic response to medication.

DISCUSSION

Although most of the attendees responded positively to the survey results, the qualitative data displayed a degree of uncertainty on the concept and application of pharmacogenetic research. Survey results showed 10 of 31 participants disagreed or strongly disagreed that the amount of information presented was about right, which was reflected in the qualitative data by the general need for clarification. Eight of 31 attendees disagreed or strongly disagreed with the statement that enough background information was given, which further supports this notion of attendees wanting more explanation. Providing attendees time to process or an opportunity to ask questions to clarify the topic would be beneficial for disseminating results to the community on a complicated topic like pharmacogenetics. The IGNITE presentation format is not recommended for future AN/AI presentations on pharmacogenetics, at least with an audience being initially introduced to genomic medicine.

These qualitative findings highlight the need to improve engagement with the community when carrying out a pharmacogenetic research study. Attendees showed interest in

pharmacogenetic research, opening up space for dialogue. Enthusiasm came through during the discussion groups, not just for the pharmacogenetic research results, but also for information throughout the pharmacogenetic study. The clear request from attendees for frequent communication throughout the project points to the need for transparency—a part of rebuilding the trust lost with past research misconduct in the AN/AI community (Foulks, 1989; Hodge, 2012; Mello & Wolf, 2010).

Attendees wanted to know more about the application of pharmacogenetics to their daily life. Many of the comments elicited fascination of the possible benefits of individualized medicine. A question-and answer-session after the presentation would offer attendees a chance to clarify and process the dense information presented. This type of group engagement is crucial for addressing health disparities among targeted populations; the insight obtained offers necessary perspectives in order for results to provide applicable and helpful outcomes for the community (McDavitt et al., 2016). Moreover, a question-and-answer-session would be particularly helpful for attendees who are learning about the concept of pharmacogenetics for the first time. This group engagement approach would instill cultural relevance to the results dissemination process, further embedding the project in the foundations of CBPR.

Pharmacogenetics introduces a new aspect of health education when disseminating pharmacogenetics research results to the community and when implementing pharmacogenetics tools in health care delivery. In the Forum, attendees were curious about pharmacogenetics but wanted the explanation to be relatable, a finding similar to others (Goldenberg et al., 2013; Shaw et al., 2013). Educating AN/AI community leaders and tribal health care administration on genetics prior to study initiation has been described; however, community-wide education on genetics in relation to dissemination was not discussed (Boyer, Mohatt, Pasker, Drew, & McGlone, 2007). Pharmacogenetics is a complex topic, and an involved explanation of the term pharmacogenetics should be included to achieve a clear delivery of pharmacogenetic research results to the community.

Interestingly, many attendees expressed they would like their provider to have access to their personal genetic results, whereas previous studies reported hesitation with having genetic information available for provider review (Boyer et al., 2007; Shaw et al., 2013). Individual return of genetic results must consider several layers of information. Beskow and Burke (2010) suggest research participant's return of genetic results depends on context and describe how

CBPR with disadvantaged populations may be a context where researchers need to make considerations of their strength of rationale for not providing individual results within the scope of entrustment. The SCF health care model speaks to the enthusiasm attendees expressed to involve their providers with their individual genetic results. A trusted relationship between the customer-owner and the health care system has been emphasized in the delivery of health care at SCF, and this approach has been well-received by many customer-owners (Eby, 2007; Gottlieb, 2013). Specifically, provider communication has been a long developed relationship, and the accentuation to keep providers abreast on research results that could improve services was clear from Forum attendees. The interest shown by attendees to have their providers be informed of genetic results parallels the customer-owner focused model of health care that drives the conduct of the SCF Research Department.

Limitations

There are several limitations with this case study. The generalizability of these findings is limited. The characteristics of the attendees of the Forum do not reflect the characteristics of the AN/AI population in southcentral Alaska. Moreover, characteristic information was not available for all participants for each characteristic variable (see Hiratsuka et al., 2018, "Perspectives on Disseminating Research Findings"). The sample was recruited through advertisements across a tribal health care campus. Attendees may have more thorough relationships with the health care system than most. Additionally, the pharmacogenetic research presentation was the last of three presentations during the research forum. The ARS responses and group discussions may have been impacted by attendee fatigue.

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Figure 1. Pharmacogenetic Results Flyer Given to Participants
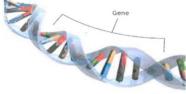

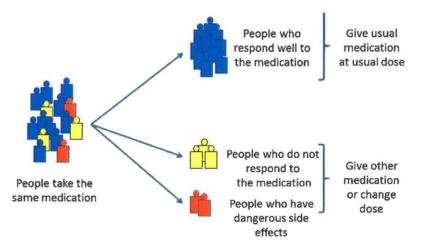## Southcentral Foundation (SCF) Research   November 2014

Prescription medications don't work the same way for everyone. It can be hard for providers to predict who and how a person will respond to a drug.

Pharmacogenetics is the study of how genetic differences influence response to drugs.

Researchers at SCF partnered with scientists at the University of Washington to study how pharmacogenetics could help providers better select the drug and drug amount (dose) a person should take.

People take the same medication

People who respond well to the medication — Give usual medication at usual dose

People who do not respond to the medication

People who have dangerous side effects — Give other medication or change dose

Adapted from: Evans and Johnson, *Annu Rev Genom Hum Genet* 2:9-39 (2001)

In our study, we discovered that certain genes (e.g., VKORC1, CYP2C9, and CYP2D6) occur more frequently in Alaska Native people.

We are still learning how differences in VKORC1, CYP2C9, and CYP2D6 genes affect SCF customer-owners. In our research project we found that about 60 out of 100 of our Alaska Native research participants had the VKORC1 gene. About 5 out of 100 of our participants had the CYP2C9 gene and the CYP2D6 gene. People with these genes 1) may be more sensitive to the drug warfarin*, 2) may require a smaller warfarin dose, 3) if given a standard dose of warfarin, could be at increased risk of bleeding, and 4) may not respond as well to the drug tamoxifen*.

* Warfarin is a blood thinner used to prevent stroke and tamoxifen is used for breast cancer.

These study findings may be used to improve the health of Alaska Native people across the country.

SECTION III

Section III of this special issue includes feedback from the community about the Alaska Native Health Research Forum, a summative evaluation, and recommendations to improve communication with Alaska Native and American Indian people about research.

FUTURE DIRECTIONS IN DISSEMINATING RESEARCH FINDINGS TO URBAN ALASKA NATIVE PEOPLE

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Abstract: Southcentral Foundation (SCF), a tribal health organization based in Anchorage, Alaska, operates and plans health care services in response to the priorities and tribal values of Alaska Native and American Indian (AN/AI) people, including traditional concepts of wellness, reciprocity, and working in relationship. In an effort to better incorporate AN/AI priorities and values in research dissemination, the SCF Research Department hosted the Alaska Native Health Research Forum (Forum) in May 2016. In this paper, we describe the communication strategies used by the SCF Public Relations Department, which were shared with Forum attendees, describe attendee recommendations for researchers to consider and implement, and then discuss future directions for dissemination. Lessons learned through the Forum were 1) customer-owners are interested in learning more about research, 2) dissemination should be done throughout all stages of projects using a variety of media channels, and 3) SCF Research Department dissemination should continue to shape health care.

In this paper, we describe Southcentral Foundation's Public Relations department and the communication strategies shared with the 2016 Alaska Native Health Research Forum attendees for their feedback. We then discuss operationalizing future directions for research dissemination in this urban Alaska Native community setting.

INTRODUCTION

A full description of Southcentral Foundation (SCF) is presented in an earlier chapter along with the mission, vision, and operational principles (see Dillard, Caindec, Dirks, & Hiratsuka, 2018, "Challenges"). Within the SCF health care system, customer-owners are treated as equals and share in decision-making around their health and wellness. The SCF Research Department engaged in the reciprocal relationship SCF has with customer-owners by seeking customer-owner feedback in regards to research dissemination methodologies and asking for guidance on future directions of dissemination. Additionally, these dissemination methods can be operationalized through close partnership between the SCF Research Department and SCF Public Relations (SCF PR).

As part of the Alaska Tribal Health System (ATHS; Sherry, 2004), SCF has many diverse audiences to serve when sharing information. For example, demographics such as geography, age, sex, cultural heritage and background, education, language, and varying health needs are all considered within the customer-owner population base. Other stakeholders who must be considered are Tribal leadership, employees, Tribal partners, funders, and community partners. SCF PR helps facilitate communication to its various audiences, who are both urban and rural. SCF PR creates and disseminates all internal and external communication for the organization's audiences by collaborating with other departments and programs, such as the SCF Research Department. The aim of SCF PR is to ensure clear, consistent communication and outreach efforts that align with SCF's vision, mission, and corporate initiatives (Dillard et al., 2018, "Challenges").

SCF PR offers media outreach that falls into three categories: owned media, paid media, and earned media. Owned media is generated by an organization or its agents and is disseminated through channels it controls. Owned media includes fliers, brochures, social media, and posts on an official company blog or website. Paid media (commonly called advertising) is media activity generated by an organization. This may include sponsored advertisements on social media or the radio. Earned media refers to media activity that is not directly generated by the company but rather by other sources, such as journalists in traditional media sources (Stephen & Galak, 2012).

The primary method SCF PR reaches customer-owners is through owned media channels. This is also the most utilized mode for SCF Research. Communicating through owned channels

allows SCF to directly deliver information to customer-owners. In addition, SCF PR efforts include internal messaging to employees and communication with Tribal partners and other organizations. As a non-profit organization, SCF's efficient use of the advertising budget is used to promote the organization as a whole, rather than promoting individual services, programs, or departments. To raise awareness for a specific service, event, program, or department—like the SCF Research Department—SCF PR uses an integrated approach to its owned media channels to spread cohesive messaging through multiple platforms. In addition to utilizing SCF's resources, individual departments and programs can budget or seek funding to assist with external advertisement fees.

Within the organization, SCF leadership continuously encourages employees to think innovatively. This approach indirectly encourages employees to reflect about how they contribute to the care offered to customer-owners (Gottlieb & Tierney, 2015). With a wide range of services offered, there is a large demand for employees to focus on customer service before developing processes that can improve the internal relationships in the organization. Nonetheless, most SCF employees are also customer-owners (55% of total employee population of AN/AI heritage) and work hard to stay true to the SCF mission, vision, and corporate initiatives (Gottlieb, 2013). For that reason, SCF PR and the SCF Research Department have taken a step toward increasing communication with customer-owners regarding research conducted within the organization.

The Research Forum

In May 2016, the SCF Research Department hosted the Alaska Native Health Research Forum (Forum). The Forum was convened to obtain feedback on outreach and research result dissemination strategies used by the SCF Research Department through community dialogue. A detailed description of attendee recruitment, data collection, and data analysis are described elsewhere (see Hiratsuka et al., 2018, "Approach and Methods"). In each Forum presentation, attendees were asked to share their views on the project presented. In relation to dissemination, responses to how and where results should be shared affect the SCF Research Department and SCF PR and the ability to increase their support for the benefit of customer-owners and the scientific community. SCF PR shared with Forum attendees information about the communication strategies they used in order to gather attendees' feedback. Forum attendees then

discussed operationalizing future directions for research dissemination in this urban Alaska Native community setting with SCF Research Department staff.

Attendees were interested in learning about the background for community-level research review and the development of the SCF Research Department. They expressed interest in knowing about the premise of past and current research projects. They were excited to see and discuss research projects and results with the research staff conducting the projects. Attendees appreciated the opportunity to provide feedback on the specific research projects presented at the Forum and the communication strategies used by researchers in research dissemination. Attendees thought of dissemination as a process that should occur across the lifespan of a research project and were most concerned with the implementation of findings into changes in clinical care.

SCF PUBLIC RELATIONS COMMUNICATION STRATEGIES

To maximize communication outreach, SCF PR works with other departments in the organization for communication planning. In this planning, the SCF Research Department and PR determine timelines and tactics to maximize reach for specific situations. Tactics are based on target audiences in each circumstance. For the SCF Research Department, audiences may include leadership, providers, and customer-owners. Once the audience is identified, the SCF Research Department may request specific types of tactics to use, and SCF PR will accommodate the requests with the resources available to their department. SCF offers a wide range of owned media tactics and have the connections to assist departments with paid media options. SCF-owned media includes the organization's website, social media, internal audience blog format newsletter (the *Communicator*), external audience print newsletter (*Anchorage Native News*), fliers, and clinic-based media (Passive Education Panels [PEPs]). For this paper, each type of SCF-owned media will be introduced with examples of the SCF Research Department's uses of these types of methods. It will end with a discussion about how the department hopes to increase its efforts of dissemination and encourage other health researchers to further use these methodologies as well as partner owned media and earned media opportunities.

Website

Southcentral Foundation's website (https://www.southcentralfoundation.com/) is the external digital hub and online resource for information about the organization's history, operational principles, Nuka System of Care, leadership, services, departments, and programs, as well as SCF news relevant to customer-owners found in the "Top Stories" section. SCF's external web page averages 1,151 active users per day. Users visit an average of 1.87 pages per session with an average session lasting one minute and 40 seconds.

The SCF Research Department has a web page for SCF internal communications that contains a list of all the current staff members, their contact information, and a frequently asked questions page. Before the Forum, the SCF Research Department began developing an external web page through the main SCF website (https://www.southcentralfoundation.com/services/research/). This new external website includes staff biographies and photos of each member; a list of SCF Research Department projects, including their status (recruiting, ongoing, etc.); a complete list of the department's peer reviewed publications; and information about the tribal review process that is required before any study can begin with customer-owners. This website is an example of how working in partnership contributes to successful dissemination with the community. In this scenario, SCF PR designed the pages to be consistent with the main SCF website, allowed the SCF Research Department to guide the direction of the content, and maintains the page so it is current and interactive. This web page is unique compared with other SCF service web pages because it relays general information about the department and is also a tool for the user to navigate the tribal review process and to seek opportunities to participate in studies. Before the website went live to external audiences in January 2017, articles appeared in *Anchorage Native News* (January 2017) and *The Communicator* (January 2017) to advertise this new resource.

Attendees of the Forum appreciated the scope of the main SCF website and noted the possible use of the SCF Research Department site for future reference. Attendees mentioned the importance of research projects having an internet presence, particularly for younger community member use. They were concerned that sole use of a website for dissemination would alienate older community members as Elders may have a harder time navigating the internet.

Social Media

Social media accounts are used for engaging customers and disseminating information. SCF's most popular social media platforms are Facebook and Twitter. SCF's corporate Facebook has more than 3,100 likes, and its corporate Twitter account (@SCFInsider) has more than 1,070 followers. Women make up 81 percent of SCF's Facebook followers. The largest group of Facebook followers is between the ages 25-34, with 27 percent of that age demographic being women. Facebook posts with links (to SCF or other websites) have the highest average reach (1,339) among posts, with an average engagement of 61 post clicks and 33 reactions, comments, or shares. Women comprise 71 percent of SCF's Twitter followers. The top age group of Twitter followers is 35-44 at 53 percent.

Prior to the Forum, the SCF Research Department had not used social media for recruitment. However, the Forum recruitment flier was shared on the SCF Facebook page along with more contact information for the SCF Research Department. SCF PR created three posts on the SCF Facebook page calling for participants to register for the Forum. The posts linked to a Forum registration form on SurveyMonkey, thus giving the SCF Research Department team the opportunity to verify eligibility before the Forum and to outreach by telephone to remind customer-owners of the Forum details the day beforehand. These three posts reached 3,507 people, received 218 post clicks (leading 68 individuals to the registration form), and generated 65 likes and 46 shares. With the possibility of increasing recruitment for participation in various studies at SCF, the SCF Research Department has begun to use social media for recruitment and for updating external audiences with project updates in ongoing studies.

Attendees supported the use of social media for ongoing communication about research projects. Attendees desired social media options beyond the current corporate accounts on the Facebook and Twitter platforms. Recommendations on social media content included the use of photos and videos, providing hyperlinks to web-based media including the SCF website's pages, and directing people to additional research websites and media (e.g., National Library of Medicine).

Newsletter

The *Anchorage Native News* (ANN) is a print publication produced by SCF PR six times a year. It is a resource for SCF news, events, information, and health-related topics for customer-

owners and the AN/AI community. Stories are typically between 250-500 words and are written at an eighth grade reading level. SCF PR prints 12,000 copies of each edition; 10,000 are mailed and 2,000 are printed and distributed on the Alaska Native Medical Campus. A PDF document is available on the website. Additionally, individual stories are placed on the organization's website as Top Stories and posted on the organization's social media channels, Facebook and Twitter, for integrated communication. An article, which recapped the Forum, appeared in the June/July edition of the ANN. The recap was also posted as a Top Story on the organization's website.

Most of the SCF Research Department's submissions for ANN articles are written by department staff involved in the projects. In the past, there have been efforts by SCF PR to write the articles. However, most of the articles written are informative, descriptive of projects, or contain technical language related to the science of these projects; therefore, it is easier for SCF Research Department staff to draft an article, route it internally for edits, and then send the final product to SCF PR. From that point forward, SCF PR streamlines the article for consistency within the entire ANN issue. The SCF Research Department includes administrative support and interns in the writing process of ANN articles. This helps to translate article content from scientific language to lay language. Forum attendees were aware of the ANN, but only Elder participants routinely read articles within the newsletter making this communication channel less ideal for community-wide dissemination.

Fliers

Fliers are printed handouts with information about SCF programs or services. SCF departments and programs provide relevant information (time, date, location, program description, etc.), and the fliers are edited and designed by SCF PR. Individual departments and programs are responsible for printing, disseminating, and tracking fliers. This includes budgeting for the supplies to print fliers or for printing fees if ordering through an external printing vendor.

In preparation for the Forum, the SCF Research Department and PR collaborated on creating a flier. The SCF Research Department presented the content, and PR designed the flier. The SCF Research Department and SCF PR used fliers to recruit from the targeted audience for the Forum. SCF Research Department staff distributed the fliers at various locations, both in SCF buildings and in external areas. The SCF Research Department placed fliers in lobbies, in external tribal and corporation buildings, and in locations frequented by customer-owners.

Electronic versions were featured on the SCF Facebook page, Twitter, and in *The Communicator*. Fliers are the most common technique used by the SCF Research Department for recruitment.

Within the Forum, attendees endorsed continued use of fliers as a form of communication on open research studies. They expressed interest in continued use of hard copy fliers at clinic and community locations and cross listing of electronic fliers on websites and social media platforms. They also mentioned being interested in receiving the flier in their traditional mail, emailed to their personal addresses, and shared through SCF's patient portal (see Dillard et al., 2018, "Challenges").

Table 1
Dissemination Methods at Southcentral Foundation

Method	Target Audience	SCF Research Example
Website	Customer-owners	Online source accessible from all
	Potential scientific partners	computers
Social Media	Customer-owners	Facebook
	External affiliates	Twitter
Newsletter	Customer-owners	*Anchorage Native News*
	Employees	*Communicator*
Fliers	Potential study participants	Clinic based recruitment
	AN/AI community	(tables or on message boards)
Clinic Based Media	Customer-owners in clinics	Passive Education Panels

Clinic-Based Media

Passive Education Panels (PEPs) are the television monitors throughout SCF's campus and facilities that play a variety of educational, informational videos and slideshows. SCF PR works with SCF technical support on PEP content. In total, SCF controls 25 PEPs located throughout various facilities in Anchorage, Wasilla, McGrath, and Iliamna. The Anchorage Native Primary Care Center has approximately 9,800 customer visits per month; therefore, the potential reach for messages targeting the customer-owner population through this form of media is significant.

SCF PR reviews and oversees the content of all forms of media that represent SCF, including PEPs. Looking ahead, the SCF Research Department would need to work with the co-management of PEPs to develop this mode of communicating with customer-owners. PEPs offer a way to advertise recruitment, give study updates, and disseminate findings. PEPs are an area of

interest for the SCF Research Department, and they are learning more about the process of getting content shared through this method, including software to develop content and networking to establish relationships with videographers. While further effort is made on this front, the SCF Research Department continues to value the face-to-face engagement of manning tables in Anchorage Native Primary Care Center and interacting with customer-owners. Attendees universally had awareness of the PEPs due to routine health care service utilization at SCF. Attendees commented on the lack of variety of information shared on the PEPs. Additionally, attendees noted that clinic based staff would turn down or off the audio, making video content less actionable. Regardless, attendees felt that the PEPs were under-utilized as a form of research project dissemination.

Partner-Owned Media

During the course of the Forum's semi-structured facilitated discussion groups, attendees requested use of SCF community partner-owned media. Attendees suggested health researchers present their current projects and research results as call-in program discussions on AN/AI specific radio programming such as KNBA 90.3 FM, an Alaska Native radio station located in Anchorage, Alaska, and the Alaska Public Media's weekly health program. Attendees spoke about wanting to see newspaper and newsletter stories on health research recruitment, conduct, and implications in rural Alaska newspapers, urban news outlets, and Alaska Native corporation newsletters. Attendees also mentioned interest in the use of earned television media spots on local and regional news programs for research project dissemination, in particular showcasing the translation of research into changes AN/AI clinical care.

DISCUSSION

Within other settings, researchers largely determine areas of research focus with limited input from patients or the health care system. Dissemination is usually a one-way channeling of information largely focused on scientific publication at the end of a project. Within SCF, however, there is a clear expectation of reciprocity among researchers, customer-owners, and the SCF health care system (Gottlieb et al., 2008). The SCF Research Department was created to address health topics prioritized by customer-owners and leaders, to improve care, and to create a

healthier community. Reciprocity is a core value among most AN/AI communities. SCF exemplifies this value by operating in partnership with customer-owners around their health care decisions (Gottlieb et al., 2008). The SCF Research Department used the Forum to obtain feedback and plan for changes to their dissemination practices. We learned sharing research updates in addition to results is clearly an expectation of customer-owners in return for their participation in studies. Each of the lessons learned from the Forum fit within the cultural values that SCF is built upon.

Considering the quantitative and qualitative data presented in the three case studies as well as the summative evaluation, several key lessons learned through the Forum emerged: 1) customer-owners are interested in learning more about research, 2) dissemination should be done throughout all stages of projects using a variety of media channels, and 3) SCF Research Department dissemination should continue to shape health care. We apply these findings to futures directions of dissemination methods through interdepartmental partnership, connected by SCF values.

It was clear that customer-owners are interested in learning about research activities. Across the wide portfolio of research studies, customer-owners expressed continued willingness and interest to engage as participants, including discussing sensitive health topics. The high interest reflects the ownership that customer-owners take in shaping their health care. Contributions to studies illustrate the cultural value of reciprocity by forwarding the benefits onward. Customer-owners willingly participate with the expectation that their descendants will benefit from the research.

SCF PR's goals include continued and expanded collaboration with SCF departments and partner organizations to develop strategic communication plans. This initiative will help meet the variety of media channels customer-owners are seeking from research. Rather than using a tactic-based approach (producing content and disseminating to customer-owners), SCF PR would like to use a strategy-based approach (using metrics, data, and current best practices) to create more defined objectives to attain organizational communication goals. The effort to use a strategy-based approach is ongoing, and collaborating with departments across the organization is crucial to successful research dissemination that reflects the community's feedback.

SCF PR's strategy-based approach is well suited for the SCF Research Department's effort to improve the process of dissemination. Customer-owners voiced that they want to

continue being involved and well-informed about the studies in their research department. The SCF Research Department's web page has been customized with the input of SCF PR, making it engaging for customer-owners. In an effort to expand dissemination as an ongoing communication process throughout studies, as opposed to just an output once the project ends, the SCF Research Department, in partnership with SCF PR, has a wide range of tools to put this into practice. Going beyond a one-way program description, the web page is interactive—a place where customer-owners can go for current and completed projects, team biographies, and other research resources. These initial efforts into the web page design respond to the customer-owner request for a place where customer-owners can learn more about projects earlier in the research process. In addition to the web page, the SCF Research Department is increasing efforts into all SCF-owned media channels with more creative and strategic dissemination methods based on customer-owner feedback at the Forum. Attendees shared a wide variety of thoughts about methods of dissemination. This included their interest of being informed at all stages of research, more use of imagery, small amounts of information with direction to find more detailed information, suggesting use of humor, and providing positive feedback about incorporating more culture into dissemination methods, in particular AN/AI language.

By using the SCF Research Department's web page as a central location for all research information, there is increased opportunity to promote and release information regarding research studies conducted by the organization. In the future, PEP monitors are an area the SCF Research Department hopes to use more, and then link materials back to the web page either through customer-owners being directed to the web page for more information or by uploading materials to the web page. Most methods of SCF-owned media can be linked back to the web page.

During the Forum, customer-owners described dissemination as a practice that is continuous. Research has conventionally approached dissemination as a final step in projects. This lesson learned from customer-owners re-defines dissemination as an ongoing piece built into all stages of the research project's life. So in addition to expanding the material of dissemination, the effort to provide updates and transparency in research with customer-owner participants is important. Since the Forum, the SCF Research Department has been granted additional funding in order to continue the dialog about dissemination with customer-owners. For the next four years, the project team will hold quarterly discussion groups with customer-owners to gain feedback about the department's different forms of dissemination methods, as well as new efforts incorporating

this feedback. This will allow increased collaboration with the SCF Research and PR Departments. Conducting research within a tribal health organization such as SCF fosters the implementation of feedback, especially in exploring dissemination. Aligning with the value of reciprocity is again very fitting for this community. The willingness to engage and share provides the foundation for gathering data for research. In turn, this effort made by customer-owners can and should be reciprocated with transparency and project updates throughout project life.

The common thread of reciprocity informing dissemination moves into the third lesson learned from the Forum: attendees want SCF research findings to improve their services. Customer-owner-driven services mean continually shaping health care to the needs of the people (Gottlieb et al., 2008). The SCF Research Department aims to conduct meaningful research that aligns with the health priorities of the organization and community. Now when sharing about a study, the SCF Research Department has begun to state which corporate objective the study aligns with in order to more clearly illustrate how the study is contributing to the improved health of AN/AI community. Customer-owners continue to actively engage with and show high interest in participating in research. As discussed, attendees described dissemination as necessary in all stages and want it to be provided through multiple methods. A complete cycle of this process would be to ensure that findings and results return to the health care system, to inform providers and customer-owners and ultimately to improve services. With this third piece in place, attendees offer a model of dissemination that fits the health care model into which the SCF Research Department is built.

The customer-owner recommendations gathered at the Forum reflect organizational values that can continue to be integrated within the SCF Research Department's dissemination process. The value of reciprocity interconnects the lessons learned and informs practice within research. Customer-owners demonstrated high interest in all the stages of research. Tribally owned and operated, customer-owners continually shape their health care system. Giving back is practiced across the organization in many forms. For research, customer-owners participate and drive the studies that directly impact their services. For the SCF Research Department, honoring contributions by redefining dissemination matches the values practiced as an organization. Collaboration between SCF PR and the SCF Research Department is a viable partnership in implementing the feedback from customer-owners in staying engaged through multi-directional modes of dissemination.

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