

APPROACH AND METHODS OF THE 2016 ALASKA NATIVE HEALTH RESEARCH FORUM

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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 (Bowe Katy, 2002; Bromley, Mikesell, Jones, & Khodyakov, 2015; Filippi et al., 2012; Gottlieb, 2013; Guillemin et al., 2016; Hiratsuka, Brown, Hoefft, & 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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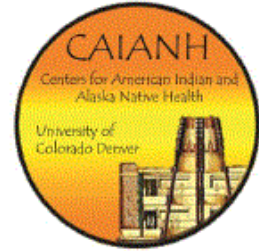
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AUTHOR INFORMATION

Dr. Vanessa Y. Hiratsuka and Dr. Jaedon P. Avey are senior researchers in the Research Department at Southcentral Foundation in Anchorage, Alaska. Julie A. Beans and Lisa G. Dirks are researchers in the Research Department at Southcentral Foundation. Karen Caindec serves on the Board of Directors for Southcentral Foundation, and Dr. Denise A. Dillard is the director of the Research Department at Southcentral Foundation.

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)