

## ALASKA NATIVE HEALTH RESEARCH FORUM: PERSPECTIVES ON DISSEMINATING RESEARCH FINDINGS

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*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 (Bowe Katy, 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%

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**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%
<i>Anchorage Native News</i>	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%
<i>Anchorage Native News</i>	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%
<i>Anchorage Native News</i>	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%
<i>Anchorage Native News</i>	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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