

## 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

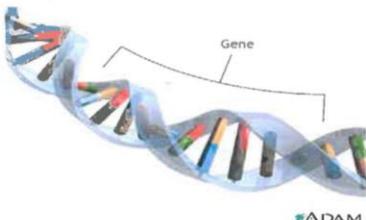
### Southcentral Foundation (SCF) Research

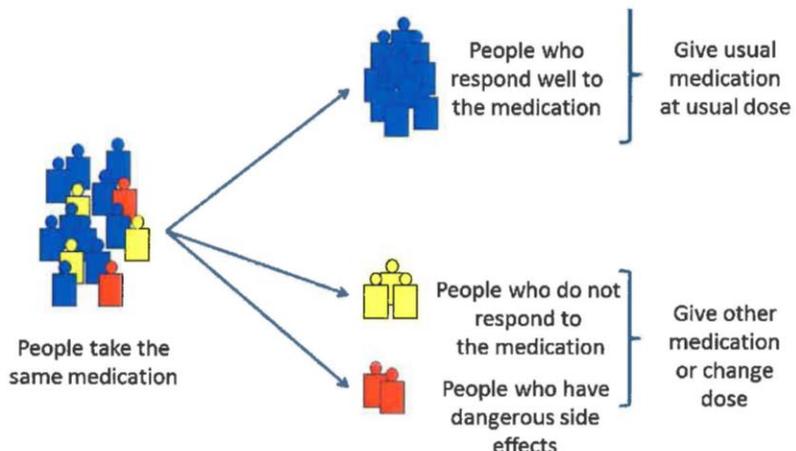
November 2014

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.





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.