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Partnership with the Confederated Salish and Kootenai Tribes: Establishing an Advisory Committee for Pharmacogenetic Research

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Abstract

Background—Inclusion of American Indian and Alaska Native (AI/AN) populations in pharmacogenetic research is key if the benefits of pharmacogenetic testing are to reach these communities. Community-based participatory research (CBPR) offers a model to engage these communities in pharmacogenetics.

Objectives—An academic-community partnership between the University of Montana and the Confederated Salish and Kootenai Tribes (CSKT) was established to engage the community as partners and advisors in pharmacogenetic research.

Methods—A community advisory committee, the Community Pharmacogenetics Advisory Council (CPAC), was established to ensure community involvement in the research process. To promote bidirectional learning, researchers gave workshops and presentations about pharmacogenetic research to increase research capacity and CPAC members trained researchers in cultural competencies. As part of our commitment to a sustainable relationship, we conducted a self-assessment of the partnership, which included surveys and interviews with CPAC members and researchers.

Results—Academic and community participants agree that the partnership has promoted a bidirectional exchange of knowledge. Interviews showed positive feedback from the perspectives of both the CPAC and researchers. CPAC members discussed their trust in and support of the

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partnership as well as having learned more about research processes and pharmacogenetics. Researchers discussed their appreciation of CPAC involvement in the project and guidance the group provided in understanding the CSKT community and culture.

Discussion—We have created an academic-community partnership to ensure CSKT community input and to share decision-making about pharmacogenetic research. Our CBPR approach may be a model for engaging AI/AN people, and other underserved populations, in genetic research.

Keywords

pharmacogenetics; pharmacogenomics; American Indian; Alaska Native; indigenous populations; community-based participatory research

Introduction

Pharmacogenetic research has the potential to improve drug response; however, variation is diverse across populations (1-4). Information about the prevalence of pharmacogenetic variation among American Indian and Alaska Native (AI/AN) people is largely lacking and limited data suggest that variation in American indigenous people is highly variable (5-7). We have reported the first comprehensive evaluation of pharmacogenetic variation in an AI population in the United States (8). Yet without continued inclusion of AI/AN people in pharmacogenetic studies, the possibility of implementing pharmacogenetic testing in these communities is limited.

AI/AN communities are wary of participating in research because of breaches of trust in prior research (6, 7, 9-13). Examples include instances in which academic investigators conducted studies on tribal lands without the approval or knowledge of tribal governments, determined research questions and methods without community input, published research findings in peer-reviewed journals but failed to share results in an understandable, culturally relevant form to the community, promulgated policy recommendations without attention to community priorities or involvement of community leadership, and based research questions on harmful cultural stereotypes and assumptions.

Genetic research represents an area of special concern for many AI/AN communities (6, 7, 14-21); many of the issues are well described in the American Indian and Alaska Native Genetics Resource Center, developed by the National Congress of American Indians (22). Important barriers to genetic research include concerns about privacy, misuse of DNA specimens, and fear of stigmatizing interpretations of genetic information (6, 7, 17, 19-21). In some communities, fear exists that genetic information could be used without tribal permission to oppose culturally established definitions of relatedness and family membership, qualifications for tribal enrollment, or challenge the validity of treaty rights (15, 16, 18, 21).

To overcome these concerns, AI/AN communities have advocated for a community-based participatory research (CBPR) model to transform research practices in their communities (23-33). A CBPR approach engages both researchers and communities in a partnership to define research questions to improve the health of AI/AN people and allows partners to work

together to build trustworthy research practices and reduce the risk of abuse. Different models of CBPR have been proposed, but all have at their center a commitment to shared power and a turn away from community members as “subjects” of research to participants in the research process. As part of the Northwest-Alaska Pharmacogenomics Research Network (NWA-PGRN), we have employed a CBPR approach to conduct pharmacogenetic research with AI/AN populations (6, 7). NWA-PGRN research was initiated by university-based researchers, who identified a research opportunity they thought might be of interest to tribal groups and approached three tribal organizations in Montana and Alaska about the possibility of pursuing pharmacogenetic research together and defining the area of greatest interest at each site (6, 7).

In this report, we reflect on the growth of a pharmacogenetic partnership with the University of Montana (UM) and the Confederated Salish and Kootenai Tribes (CSKT) of the Flathead Reservation in northwestern Montana within the NWA-PGRN. CSKT interest in pharmacogenetics was initially focused on cancer therapy and has since expanded to include cardiovascular medications. A key aspect of the NWA-PGRN project was the establishment of a community advisory committee, the Community Pharmacogenetics Advisory Council (CPAC), to provide community oversight and input into the research process, to guide university researchers in recognizing the community-level knowledge relevant to the project, and to navigate long-term translation of the findings into local health benefit. In keeping with the methods and values of CBPR, CPAC members are equal partners and co-researchers within the research project. In this effort to measure our progress and identify opportunities for improvement, our goals were to understand perspectives of researchers, clinicians, and community members within the UM-CSKT partnership: to what degree are the partners learning from each other, has CPAC gained understanding of pharmacogenetic research, and do UM investigators have a better appreciation of CSKT values and cultural customs.

Methods

Establishment of Academic-Community Research Partnership

Our partnership began in 2007 with discussions between researchers in the Department of Biomedical and Pharmaceutical Sciences at UM, an oncologist and a clinical coordinator at the Montana Cancer Institute Foundation (MCIF), and the Department Head and the Medical Director from CSKT Tribal Health and Human Services (THHS). Initial meetings focused on whether pharmacogenetic research would be of interest to the CSKT. CSKT physicians observed a lack of efficacy to anticancer agents and were aware of community-wide interest in improving cancer patient outcomes. Based on these early meetings and emerging opportunities, the UM-CSKT group developed pharmacogenetic research questions focused on cancer therapies and have since expanded to other therapeutic areas including cardiovascular disease. These meetings also established the need to develop the CPAC oversight committee.

UM-CSKT partners routinely present to the CSKT Tribal Council to request approval from Tribal leaders to initiate objectives of the project and to submit grants and manuscripts. We received approval from CSKT Tribal Council in May 2009 to submit a grant to form the

NWA-PGRN, which includes the groups in Montana (UM, MCIF, and CSKT THHS), researchers at the University of Washington, and two other tribal-academic partners in Alaska (6, 7). Funding for the NWA-PGRN started in July 2010 and includes a subcontract to CSKT THHS.

Formation of Community Pharmacogenetics Advisory Council

CPAC assures Tribal input into the research project and strengthens the UM-CSKT partnership. The Department Head and the Medical Director of CSKT THHS identified potential CPAC members who would provide broad community perspectives (demographic characteristics in Table 1). THHS Department Head sent invitations to join CPAC and the first meeting was held November 2010. CPAC consists currently of five individuals.

Monthly CPAC meetings provide a forum to review study progress, discuss pharmacogenetic research and culturally appropriate research practices, and the potential for pharmacogenetic testing in Tribal Health. A UM graduate student (C.T.M.) is the primary coordinator of CPAC gatherings. The primary research investigator (E.L.W.) works closely with C.T.M. to develop agendas and manage CPAC reimbursements. C.T.M. and E.L.W. attend meetings with other UM researchers (M.A.P. and E.A.P.). In early CPAC meetings, UM researchers established the agenda and led the conversations pertaining to research topics. As the partnership developed, however, CPAC members gained a sense of ownership of the project. Community members directed CPAC meetings by providing cultural presentations for orienting university researchers to CSKT beliefs and knowledge systems, offering insight into community dynamics relevant to the pharmacogenetic research activities, and leading dialogue on health issues of particular concern to the community. Agendas are flexible and meetings often go “off topic” to address concerns and questions that arise.

Building Capacity for Pharmacogenetic Research: Sharing Knowledge

One of the major goals of the partnership was to facilitate bidirectional learning between UM and CSKT. Academic researchers have given presentations during CPAC meetings and held two workshops to increase community knowledge of pharmacogenetics: Genetics Education for Native Americans (GENA®) (Native American Cancer Initiatives, Pine, CO) and nDigiDreams Digital Storytelling (Santa Fe, NM).

The 2-day GENA® workshop (May 2011) provided a science curriculum specifically tailored to AI/AN participants to increase genetics knowledge and assist the community with informed decision-making regarding participation in genetic research. GENA® was developed and presented by Linda Burhansstipanov, MSPH, DrPH (Cherokee Nation of Oklahoma), a public health educator, and Lynne Bemis, PhD, a biochemist and researcher. GENA® workshops have been implemented in AI/AN communities for over a decade and a 38% increase in participants' knowledge in genetics has been reported (34, 35). The workshop held with the CPAC consisted of educational modules on the basics of cell biology, genetics, pharmacogenetics, and CBPR. The GENA® curriculum is designed as a series of presentations linked with hands-on activities and interactive learning exercises. The program also featured a review of ethical issues in research with AI/AN communities and

interactive discussions of culturally appropriate ways to talk about genetic research within the CSKT community.

The 3-day nDigiDreams workshop (February 2012) integrated the oral tradition of storytelling with technology to train academic and community partners in the art of creating digital stories on health and wellness (36). UM researchers and CPAC members each produced a personal story with a collage of images, music, and narrative. The workshop helped UM and CPAC participants develop skills for disseminating ideas through visual media, and importantly, gain insights into the life pathways that led to working with each other.

The CPAC facilitated fundamental teachings for academic researchers to ground them in an understanding of the CSKT people. CPAC members from the Salish-Pend d'Oreille and Kootenai Cultural Committees provided cultural presentations at CPAC meetings and a center-wide NWA-PGRN meeting to educate academic partners about CSKT history, the relationship with the land, cultural beliefs and practices, and local community protocols.

Developing an Academic-Community Partnership: Evaluating Our Progress

As part of our shared commitment to building a sustainable, trust-based partnership, we undertook a mixed-methods approach to assessing our progress. These activities were not undertaken as human subjects research, but rather as a self-evaluation of our partnership, thus no Institutional Review Board (IRB) review was required. All partners, including research, clinicians, and CPAC members took part in the assessment. In the quantitative portion of the self-assessment, CPAC members filled out a survey on the effectiveness of CPAC meetings and workshops in enhancing knowledge in pharmacogenetic research and participation in meetings. The survey, developed by C.T.M. with input from S.B.T. and E.L.W., consisted of Likert scale and open-ended questions (Table 2) and was distributed at a CPAC meeting (June 2013).

For the qualitative portion of the self-assessment, interview questions were developed by C.T.M., S.B.T., R.J., and E.L.W. (Table 3). C.T.M. conducted interviews (March and April 2014) with researchers and clinicians (UM, THHS, and MCIF) and CPAC members; E.L.W. interviewed C.T.M. Interviews explored perspectives of the academic-community partnership to better understand the exchange of knowledge. CPAC (n=5) and researchers/clinicians (n=7) were each asked questions about the partnership (Table 3). As a matter of convenience, interviews were conducted at participants' place of work with one exception of a participant who traveled to the UM campus. Interviews were audio-recorded and lasted approximately 30 minutes. A constant comparison approach was used as the qualitative analysis methodology to identify and refine themes in the transcripts (37-39). C.T.M. and E.L.W. read and reviewed the transcripts, C.T.M. coded each transcript, and the two authors met weekly to discuss the main ideas and themes emerging from the data. Themes are categorized in Table 3, and the results of the interviews are presented individually by theme. All interviewees are co-authors of the present manuscript and were given the opportunity to provide input and clarify ideas and to approve the inclusion of their quotes.

Results

Community Engagement in Pharmacogenetic Research

Survey results suggest that CPAC meetings and workshops were effective in conveying pharmacogenetic knowledge: the average score prior to joining the CPAC was 4.5 [scale from 1 (considerable knowledge) to 5 (no knowledge)], suggesting little to no foundation in pharmacogenetics knowledge; the average score improved to 2.75 subsequent to joining the CPAC, indicating that CPAC members felt their knowledge of pharmacogenetics had increased. Not only did the average score improve, but also every CPAC member reported an increase in knowledge. Furthermore, survey showed that members were more supportive of research since joining CPAC. One member who had previously stated feeling “suspicious” of pharmacogenetics reported later: “After seeing the potential for medical breakthroughs in helping tribes, I am more inclined to support guided research, especially in the area of informing and educating the population.” CPAC members reported that the GENA® workshop helped expand their understanding of genetics and pharmacogenetics (40). For example, one member stated, “I got an idea about genetics and DNA and Indian people. It has spurred me to explore the subject more.” CPAC members reported that the nDigiDreams workshop was helpful and would be useful for communicating pharmacogenetic research (41). CPAC feedback indicated that community engagement efforts have been beneficial, but continued education efforts are important.

In survey responses and regular CPAC meetings, members have encouraged researchers to engage the CSKT community more broadly, which has resulted in multiple presentations at CSKT community events (i.e., health fairs, summer programs, and Salish Kootenai College seminars). Moreover, CPAC has engaged in the research outside of attending CPAC meetings, which highlights their investment in the project. CPAC members accompanied UM researchers and THHS staff during presentations to the CSKT Tribal Council in February 2013, February 2014, and September 2014 to seek approval to submit grant applications and manuscripts generated from the research (7, 8, 42). Additionally, one CPAC member has written several articles in the *Char-Koosta News*, the Tribal newspaper, discussing research results and increasing community awareness and education about the project (40, 41, 43-50).

Academic-Community Partnership Development

NWA-PGRN researchers represent diverse backgrounds, including academics and physicians, and have different interactions with CPAC. A Tribal Health physician described her dual role as a researcher and a community member:

I was involved from the beginning of the development of the CPAC and trying to get community members involved and identification of community members...I felt my role was sort of this, ‘the liaison’, being a scientist by training and a tribal member, being able to understand both sides.

NWA-PGRN researchers described early CPAC meetings as uncomfortable, one-way interactions. As one UM researcher observed:

I think the first couple of [CPAC meetings] were really just quiet. I really felt like I was just up there as this researcher from Missoula who didn't know anything, "What was I doing up there anyway?" And the CPAC also feeling, "What is she doing here?" Those first few meetings were tough because we [UM researchers] just didn't know how to proceed or how to even start this whole process. That was really hard because we went up [to CPAC meetings] and had all these things we wanted to talk about and get feedback from and we didn't. And I think it was mostly because [CPAC] didn't feel comfortable talking to us.

A CPAC member made a parallel observation: "When strangers come together and people talk about things that one side might not quite understand what it's all about, you know there's going to be a lot of mistrust... A person might not be open right away and want to share things." Another CPAC member described an initial skepticism of the research project, "At the very beginning I was kind of against it, I thought we were being treated like guinea pigs. I've always thought that we [American Indian people] were the first ones to be worked on." Additionally, a Tribal Health physician spoke of early impressions:

I remember being really intrigued by the idea and excited, but of course also really nervous and you know a little suspect probably, just in terms of you know: Why? Who? What? Where? When? Asking all of the questions and trying to figure out: 'Is there an angle?' 'Is there something [to be concerned about]?'

The CPAC commented on how their views had changed from skeptical to supportive, specifically, they supported the project's research approach. One CPAC member applauded the "interaction with the Culture Committees, [Tribal] Council, our Department Head, our Medical Director. A lot of times those things don't happen." Instead, past researchers would "go in there [to the community] and do all the measurements...and take data...and go to write [their] paper, and/or whatever else they need to do. It feels there was more of a relationship built here [with the NWA-PGRN researchers]." Regularly scheduled CPAC meetings helped to demystify the work being conducted in pharmacogenetics and allowed the CPAC to develop a rapport with the researchers, alleviating some of the concerns and mistrust of the research enterprise. As one CPAC member noted, "When I first came on board [the CPAC] I had lots of questions and lots of doubts. And I'm really happy that my doubts have been satisfied."

We identified key factors facilitating CPAC involvement and continual participation in the research. Some CPAC members said that a desire to learn something new spurred involvement. Others mentioned participating in research with a potential to benefit their community as a motivation:

I think it's the possibilities of finding some cure or something that could help future generations as far as diseases and sicknesses. Every day we are losing so many people to different things...And I think research to me, gives me hope that someday, somewhere down the line there's going to be something discovered, something found.

Some noted that the social dynamic of the group and opportunities to discuss health topics of interest to CSKT community have contributed to continued participation. One member

discussed his initial motivations for CPAC participation as learning about health issues affecting his family, but then added that social aspects of the UM-CPAC group maintained his participation:

First is, I want to know more about it personally, from my personal situation with my nephews and my sisters. I want to know more about what is going on...And the second is the social and informational relationship with everybody on the CPAC. I really enjoy that, and that's why I come back. I don't miss any meetings unless I am out of town. I know I missed a couple this past summer and I really felt that I missed something. Did I miss information? Did I miss people? It's the social environment really that I enjoy. I enjoy that kind of cross discussion of things.

A Tribal Health physician added that the partnership between researchers and the CSKT community was like a "courting relationship" that "takes a lot of 'getting to know' you kind of interactions, but it didn't take long to become comfortable with what I was hearing in terms of the approach and the kinds of questions that were being asked along the lines of cultural appropriateness." CPAC agreed that the development of the partnership and consistent monthly meetings had a positive impact on their commitment to meet with the group and helped build trust in cross-cultural relationships. One member regarded transparency as an essential characteristic of the partnership: "It's not secret, I mean [NWA-PGRN researchers] are open and [they] can go to the [Tribal Council] and tell [Tribal Council members] exactly what [they're] doing and not hiding anything. That's what I like, I like the open part of it."

As the group continued to convene, NWA-PGRN researchers reported increasing levels of comfort sharing pharmacogenetic research information with CPAC, and engaging in productive dialogue and interactions. One of the goals in forming CPAC was for the members to act as advisors. One researcher recounted how CPAC has taken on this role and claimed a degree of ownership of the project:

I feel that [the CPAC] feel comfortable asking questions...In the beginning, the CPAC were really passive participants. I didn't feel that they were active partners. I think the best example [of this increase in participation] is when we were brainstorming at the last meeting and they were coming up together with all these ideas of what you [C.T.M.] could do, how you could try different things...to recruit for [the research project]. One after the other they were coming up with these great ideas and just moving forward with them.

The UM-CSKT partnership has helped CPAC and researchers shift from unfamiliarity to friendliness. Researchers felt that direct interactions with community members have made the research more personalized and gave a "face to the community." One researcher discussed the social interactions of a CPAC meeting as well as their support in the research project:

I feel [CPAC and researchers] can sit in a room; we can talk at the beginning of each meeting about personal lives and about where we are from. And they do care about what I'm doing, they care about the project, and they understand the research that I do with them is my [thesis] project. And I think at the same time letting them

know I want their input, they have also realized...they have a responsibility to help me with my research and make sure that I'm successful. Because I think that comes from [CPAC] trusting what we're doing and trusting that this is a good thing... I remember [a CPAC member] told me, 'Oh yeah you have to get this going and you've got to do this for your research...and I know you're going to be graduating with your Master's soon. What are the next steps?'

Partnership Fosters Bidirectional Learning

CPAC and researchers were asked about what they had learned from each other through the partnership. CPAC responses largely focused on what they had learned about pharmacogenetics. One CPAC member talked about having a basic understanding of genetics but was surprised to learn how genetics could be playing a role in drug response:

I had never really thought about drugs, how they act, and how they react, and how they do what they're supposed to do. And how that might vary from person to person or from group to group because of the gene pool in that group. I had never really thought about that. I got the basic understanding of how the chemistry is supposed to work in treating cancer and how the chemotherapy is supposed to work and how that might be affected by the genes of the person and how to test and control for that to see if the different genes really do have an effect on the effectiveness of the drugs.

In addition, a member said, "being a part of this group has really actually made me want to learn how genetics works, how pharmacogenetics works." Another commented "I have learned a lot about DNA...I know it enough to know where I can find out more about it."

NWA-PGRN researchers noted what they learned culturally working with CPAC and the CSKT community. Some researchers talked about the importance of listening. One researcher stated:

There are cultural traditions related to elders and...letting them speak first. Which I knew something about, but seeing that in action in the community is different. Maybe doing a little more listening and a little less talking than you see a lot in non-Indian cultures...Maybe learning to listen a little more. Concepts of time are a bit different...[We] think that this is the most important thing in the world but maybe somebody else doesn't.

Tribally affiliated researchers shared that, while their Native background provided them with cultural familiarity, conducting community-based work provided advantages. One reflected that:

As a tribal member, although not from the CSKT community, there is some cultural knowledge that I have that has prepared me and translated over in working with the CPAC. And at the same time, there is a lot of knowledge that I don't know and have learned and is even more important that I continue to listen and be patient through the partnership.

Another observed that CPAC “takes ownership and have really valuable and different opinions than I would’ve had about this topic or that topic...so I think I’ve learned, again... about the cultural piece of CPAC.”

Partnership Shapes the Research

CPAC members were asked how the partnership affected the way they think about research; they described the benefits of the community-based model and how it has contributed to their receptiveness of the research. One member stated, “I think the attraction was the authentic community involvement. Because I’ve been to grad school, and I’ve participated in national research, and I know how research is often conducted. I know it certainly wouldn’t prompt me to participate in any research. But authentic community-involved research, I definitely would.” Another member commented on aspects that contributed to her positive experience with research:

Actually it has [prompted me to participate in research]. It’s interesting, the whole IRB process...having the [NWA-PGRN researchers] come in asking us questions about what we think about this or think about that, before going to IRB. I think that’s interesting. I think that it’s something that I haven’t been a part of before.

Most CPAC members expressed willingness to participate in future research projects, as long as CBPR principles adopted by the NWA-PGRN were incorporated. Specifically, “I think that [new researchers] would have to do the same things that [NWA-PGRN researchers] did. I think the most important thing would be to go to the Culture Committees and get their take and find out what they have to say because if you don’t have their buy-in, it’s pretty hard to even move forward past that point.” In addition, the CPAC mentioned their support for younger generations to become involved and to participate in research.

Researchers were asked how the partnership has impacted their work. One researcher commented on the cultural knowledge she has learned from CPAC members:

You adjust your thinking and you adjust your approach. You come from a society where everything is go go go, fast fast fast, get the answer. If you don’t come up with the answer very quickly in our society, people think you’re not as smart as somebody else...I notice [now] when someone is not speaking up and I will wait for them.

Another researcher described how this partnership provided her with cultural knowledge and prompted her involvement in other CBPR projects outside of NWA-PGRN:

Some of the early experiences I had on the pharmacogenomics project have helped in creating new projects related to cancer and community engagement. For example, we created...brochures to work with clinicians using a culturally appropriate approach. And these are all working with Native groups...So for all of these projects, some of the background I received from the pharmacogenomics exposure were really helpful in terms of understanding the cultural pieces better.

One researcher discussed how “family is important, lineage is important” to his Tribal patients and he has worked to incorporate that knowledge into his treatment plan: “Makes us realize that if we are talking to someone about, ‘Ok your treatment for cancer and here’s

what we are going to do,' you're not just talking to that person. You're talking to the whole extended family. They're all going to get involved. So I always encourage them to bring their whole family in to talk."

Discussion

AI/AN communities have historically been wary of participation in genetic research, and breaches of trust in prior genetic research are well known. Pharmacogenetic research has led to the development of tests to individualize drug therapy, but implementing these tests will be limited without participation of AI/AN populations in the research. Guided by the principles and values of CBPR, we have established a partnership between academic researchers, CSKT Tribal Health leaders, and CSKT community members to pursue pharmacogenetic research with AI/AN people. One of the most essential CBPR components of the research project has been the formation of CPAC to develop bidirectional expertise, provide community oversight, and ensure that the interests of the CSKT prioritized. CPAC meetings have helped increase community knowledge, involvement, and engagement in pharmacogenetic research and provided the CPAC with tools to have informed discussions about the research project. CBPR engagement activities have also helped guide the researchers in a culturally sensitive direction.

Academic and community partners reflected on their views of the partnership and clearly saw benefits to using CBPR as a foundation to develop bidirectional cultural and research competencies. Although community partners discussed their initial concerns about the partnership, continued participation and deliberations with academic partners has helped to create a more positive outlook on research. For instance, community partners expressed a new level of interest and openness to research, and felt more equipped to participate and direct future research projects conducted in the CSKT and other tribal communities. For many of the academic partners, CBPR was a new endeavor and there were uncertainties about how to conduct research within a Tribal community, yet through community engagement, many of these trepidations about participating in an academic-community partnership have been alleviated. For instance, academic partners expressed an appreciation for CPAC involvement and have applied cultural knowledge in guiding the research project. These examples illustrate how bidirectional learning has occurred and has helped to create a sustainable research partnership.

Formal self-evaluation activities are worthwhile and may be useful for other researchers interested in engaging underserved communities. Having researchers participate in these activities, not just CPAC, illustrates commitment to the partnership as a site for the bidirectional exchange of knowledge. Additionally, turning the evaluative lens on themselves is an important developmental and skill-building process for researchers, who are used to being on the other side of the evaluative interaction. Assessing the partnership as the relationship grows can identify what works well and where improvements can be made, and also gives timely feedback to the group as a whole. Introducing formal opportunities for partners to reflect on what they have learned and how their participation has made a change in their thinking can provide a useful starting point for deeper discussion of the partnership

and the research goals. Furthermore, community involvement, action, and knowledge in research may provide natural opportunities for community-driven initiatives to emerge.

Our academic-community partnership approach may be a model for other researchers to pursue trustworthy research with AI/AN communities in pharmacogenetics and other genetic research studies as well. Additionally, this model may also be useful in engaging other ethnic groups in genetic research who have largely been excluded from genomic studies. The use of CBPR has transformed our research into a collaborative effort where tribal partners are involved in all aspects of the research project to ensure that community needs are prioritized. Moreover, our process helped transform individuals as a result of their engagement in these processes. Investing in meaningful partnerships grounded in the values and principles of CBPR will enable us to sustain and expand our research efforts and increase capacity for genomic research that may address health disparities in AI/AN communities.

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Table 1

CPAC Demographic Characteristics (n=5)

Characteristic	n
Age (yr)	Mean: 63.8 (Range: 60 – 68)
Gender	
Male	3
Female	2
Background	
Kootenai Culture Committee	1
Salish-Pend d'Oreille Culture Committee	1
Tribal Council Office	1
Tribal Health and Human Services	2
Tribal Affiliation	
CSKT	3
Other	2

CPAC: Community Pharmacogenetics Advisory Council; CSKT: Confederated Salish and Kootenai Tribes

Table 2
Survey Questions for CPAC Members

Questions		
Likert Scale	•	Rate your knowledge of pharmacogenetics prior to joining the CPAC
	•	Rate your knowledge of pharmacogenetics after joining the CPAC
Open-Ended		
Views on Pharmacogenetic Research	•	What were your thoughts when you first heard about pharmacogenetic research with AI/AN communities at the UM?
	•	What are your thoughts about the research since you have been involved as a CPAC member?
GENA® Workshop	•	Did you find the GENA® workshop helpful in expanding your knowledge in the area of genetics and pharmacogenetics?
	•	What were the main concepts that you learned at the GENA® workshop?
nDigiDreams Workshop	•	Do you think that digital storytelling is a useful method for communicating pharmacogenetic research?

AI/AN: American Indian and Alaska Native; CPAC: Community Pharmacogenetics Advisory Council; UM: University of Montana

Table 3
Interview Questions for CPAC Members and NWA-PGRN Researchers

Themes	CPAC Members		NWA-PGRN Researchers	
Academic-Community Partnership Development	•	How have you been involved in the partnership?	•	How have you been involved in the partnership?
	•	What motivates you to be an active part of the CPAC?	•	What is your role as a research partner?
	•	Is there anything specific about the CPAC that has influenced your continued participation?	•	Could you describe your overall experiences in the partnership? (i.e. research development, community engagement)
Partnership Fosters Bidirectional Learning	•	What has this project taught you about working with UM researchers?	•	What has this project taught you about working with the CSKT community?
	•	Have you learned anything that was surprised you? (i.e. research process, genetics)	•	Have you learned anything that was surprised you? (i.e. cultural aspects)
Partnership Shapes the Research	•	Aside from your participation in this research project, has your experience prompted you to consider participating in other research projects?	•	Are there ways that CPAC input affected your work?
			•	Has this project changed the way you do – or think about – your work?
	•	What aspect of working with the UM researchers have you found to be beneficial to the partnership?		

CPAC: Community Pharmacogenetics Advisory Council; CSKT: Confederated Salish and Kootenai Tribes; NWA-PGRN: Northwest-Alaska Pharmacogenomics Research Network; UM: University of Montana