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### Exploring Views of the Confederated Salish and Kootenai Tribes about Pharmacogenetics Research and its Translation into Tribal Health Clinics

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Title: "Exploring Views of the Confederated Salish and Kootenai Tribes about Pharmacogenetics Research and its Translation into Tribal Health Clinics"

**Abstract:**

Pharmacogenetics research has advanced our knowledge of the genetic basis of individual drug responses. Further benefits stem from the translation of pharmacogenetics research into the clinic to identify patients who are at high risk of adverse drug events. However, American Indian and Alaska Native (AI/AN) populations have not benefited markedly from genetics-guided therapeutics. A key strategy in engaging AI/AN people in pharmacogenetics research has been the implementation of a community-based participatory research (CBPR) approach, a qualitative research methodology in which a partnership is formed between the research institution and the community participating in the research. The **main hypothesis** is: *CBPR methods provide a robust basis for addressing knowledge gaps related to pharmacogenetics in AI/AN communities.* Research has demonstrated multiple positive outcomes of utilizing a CBPR approach in AI/AN populations. CBPR provides a framework for both partners to be involved in all aspects of the research process, from developing research questions to data analysis, and dissemination of research results. Early in the project, approval was given by the Confederated Salish and Kootenai Tribes (CSKT) through discussions with Tribal Health and Tribal Council to conduct pharmacogenetics research with the CSKT community. Thereafter, a collaborative university-community partnership was established with the CSKT to develop culturally relevant research strategies. Research goals from this partnership include (1) identify resources available in the area of pharmacogenomics research to facilitate community involvement and education, (2) assessment of whether pharmacogenetic testing would be feasible in CSKT Tribal Health, and (3) identification of views and perceptions regarding pharmacogenetics research in the CSKT community. We formed an oversight committee, the Community Pharmacogenetics Advisory Council (CPAC), to ensure community involvement. We also held workshops to provide education and bring awareness to the community about pharmacogenetics research. CPAC members were administered surveys to inform us about the value of the workshops and if the workshops were useful as an educational tool. Furthermore, using Likert-scale and open-ended questions, the survey assessed the degree of knowledge CPAC members felt they had in the area of pharmacogenetics and whether participation in the CPAC has improved their knowledge. Likert scales were designed on a scale of 1 to 5, with 1 reflecting "considerable knowledge" of pharmacogenetics and 5 reflecting "no knowledge" of pharmacogenetics. Seventeen healthcare provider interviews were conducted with providers in Missoula, Polson, and St. Ignatius, MT to assess their views on the potential benefits and harms of pharmacogenetics research and the feasibility of its future implementation into Tribal Health. The interviews were transcribed and analyzed using Dedoose, an online qualitative software package to identify emerging themes from the interviews. In addition, we are conducting focus groups with CSKT members and descendants who receive their healthcare through Tribal Health to facilitate discussion around the topic of (1) pharmacogenetics research with AI/AN communities, (2) its translation into Tribal Health clinics, and (3) dissemination of results to community. Five participants have been recruited thus far (of a target 32). CPAC members helped design a moderator's guide and developed recruitment tools for focus groups. Results from the CPAC survey showed that the average score of CPAC members knowledge prior to joining the CPAC was 4.5, suggesting they had little to no knowledge of pharmacogenetics research. The average score after joining the CPAC was 2.75, suggesting that CPAC members felt their knowledge of pharmacogenetics had improved. Not

only did the average score improve, but every individual member of the CPAC reported an increase in knowledge prior to and after joining CPAC. Results from the healthcare provider interviews found that participants were optimistic about future potential of pharmacogenetic tests, but voiced that such testing may have reduced acceptability, utility, and feasibility in rural/tribal practice settings. Participants in tribal community settings identified the heightened importance of genetics and the need for community leadership approval as additional considerations. Preliminary findings from the focus groups found that CSKT views were overall enthusiastic about the potential benefits of pharmacogenetics. However, participants mentioned that cultural barriers exist amongst the broader CSKT community, but discussions and education efforts could help overcome these barriers. This collaboration between UM, Tribal Health, and CSKT community created a CBPR framework that best fits the needs of the community. Engaging CSKT community partners in informal and formal discussions about pharmacogenetics research has aided in identifying priorities of the community and building mutually productive partnerships. Furthermore, this research will significantly expand researchers' and community partners' capacity that can bring about enduring change, both in how pharmacogenetic research is conducted and in its application to improving the health disparities of CSKT people.