

Perceptions of genomic medicine and technology among Native Hawaiian patients enrolled in a longitudinal healthcare engagement program

Alex Ueoka¹, Mālialani Kana'iaupuni², Chaye Kauhola², Selena Vanapruks³, Keolu Fox⁴, Leah Dowsett^{2,3}, Stacy Brown^{2,3}

¹Columbia University, ²The Queen's Medical Center, ³University of Hawai'i, John A. Burns School of Medicine, ⁴University of California San Diego

Introduction

Background

- Genome-wide association studies lack racial diversity, with 95% of participants being of European ancestry, resulting in inequities when applying precision medicine to underrepresented communities.
- Native Hawaiians and other Indigenous populations have been negatively affected by unethical research practices (e.g. unequitable benefit sharing, lack of community consultation).
- The ethical inclusion of Native Hawaiians in genomics research requires culturally respectful approaches.

Queen's Genomics Institute (QGI)

- Non-profit initiative led by Native Hawaiian physicians and scientists
- Its mission is to ensure advances in genomics-based health research benefit Native Hawaiians and all people of Hawai'i.
- As a local biobank and research engine, the QGI will lead efforts to collaborate with diverse community members, train homegrown researchers, and translate data resources into meaningful improvements in healthcare for our islands.

Study Status

- Mock focus group session held to obtain feedback for ongoing study
- The findings of the completed study will inform QGI protocols.

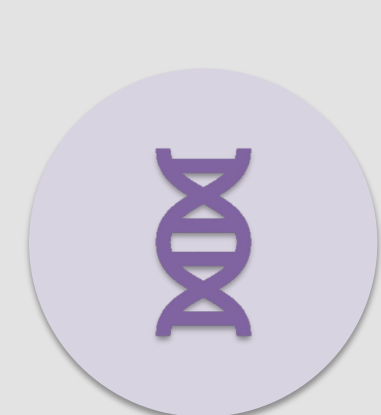


Methods

Overview

- Qualitative, focus group study
- Participants will be recruited from Queen Emma Clinic (QEC) Kilolani patients (Native Hawaiians with diabetes and structural barriers to healthcare),
- Focus group transcripts will be analyzed and coded for themes.

Focus Group Session



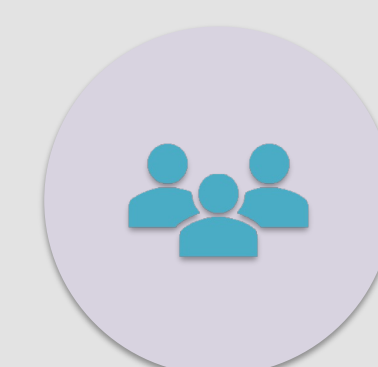
Culture-based Genetics Educational Presentation



Indigenous Data Sovereignty Presentation



QGI Presentation and Technology Demonstration



Focus Group Discussion

Focus Group Questions

- What are your reactions to the presentation and what did you learn that surprised you?
- What are your reactions to the QGI?
- What health concerns should QGI prioritize?

Results

Curriculum Feedback

- Culture-based educational materials are accessible, understandable, and meaningful.

QGI and Research Participation

Participants expressed:

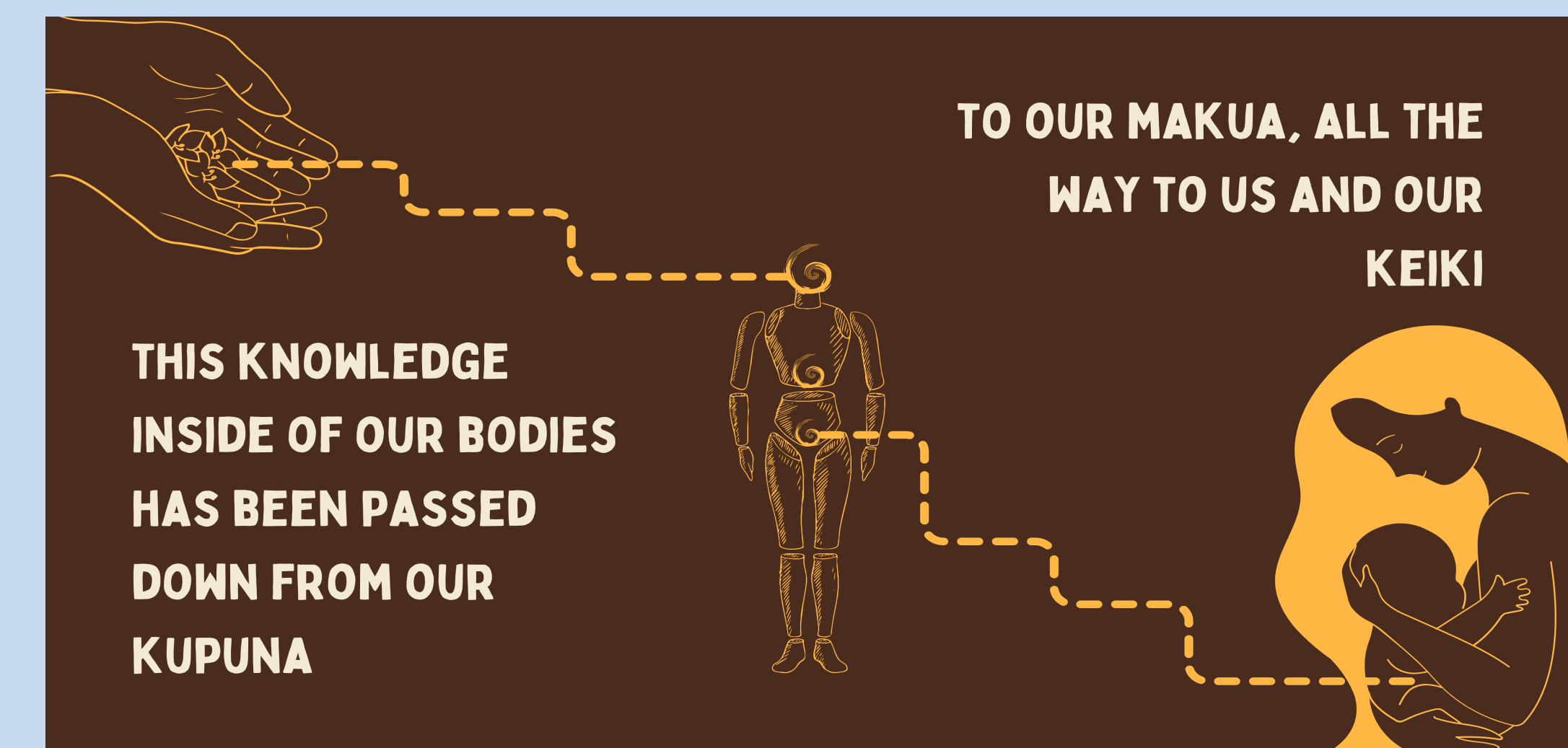
- Trust in Native Hawaiian researchers and Queen's Medical Center to oversee Native Hawaiian samples and genomic data
- The importance of transparency and continuous communication from researchers
- A desire to help others through research as both an individual and cultural value
- Interest in the idea of point-of-care access through a mobile vehicle

Research Priorities

- Cancer, diabetes, mental illness, hypertension, heart disease, and substance abuse

Discussion

- Participants expressed support for the QGI with preferences for transparency, continuous communication, and Native Hawaiian leadership.
- Participants found that educational materials would be beneficial for the whole community beyond this study.
- Mock focus group participants were biased since they work in the healthcare and/or research fields and were previously familiar with the QGI and this study.



Conclusion

- Community engagement is essential to ensure ethical and culturally respectful practices.
- The mock focus group session provided critical feedback to improve focus group sessions.
- QGI goals and curriculum were well received during mock focus group session.
- As the project continues, qualitative insights obtained will inform the development of the QGI.

References

- GWAS Diversity Monitor*. (n.d.). Retrieved June 30, 2023, from <https://gwasdiversitymonitor.com/>
- Landry, L. G., Ali, N., Williams, D. R., Rehm, H. L., & Bonham, V. L. (2018). Lack Of Diversity In Genomic Databases Is A Barrier To Translating Precision Medicine Research Into Practice. *Health Affairs*, 37(5), 780–785. <https://doi.org/10.1377/hlthaff.2017.1595>
- LorrieAnn Santos. (2008). Genetic Research in Native Communities. *Progress in Community Health Partnerships: Research, Education, and Action*, 2(4), 321–327. <https://doi.org/10.1353/cpr.0.0046>
- Singeo, L. (2007). The Patentability of the Native Hawaiian Genome. *American Journal of Law & Medicine*, 33(1), 119–139. <https://doi.org/10.1177/1009885880703300104>
- Taual'i, M., Davis, E. L., Braun, K. L., Tsark, J. U., Brown, N., Hudson, M., & Burke, W. (2014). Native Hawaiian views on biobanking. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 29(3), 570–576. <https://doi.org/10.1007/s13187-014-0638-6>

Acknowledgements

Special thank you to my mentor, Dr. Stacy Brown, for your expertise and guidance. Thank you also to Dr. Dowsett, Dr. Fox, and the Kilolani research team for your support.

Thank you to Lori Tsue and the QMC Office of Research and Development for facilitating my experiences throughout the Queen's Summer Research Internship.

Thank you also to Joann Tsark, Dr. Kathryn Braun, and the QEC staff for your critical feedback and assistance.