



# ELSI FRIDAY FORUM

## “Indigenizing Genomics and Advancing Digital Data Equity”

**Date and time:** Friday, February 10, 9am PT / 12pm ET

**Speakers:** Krystal Tsosie, PhD, MPH, MA & Phillip Wilcox, BForSci (Hons), PhD

**Moderator:** Josephine Johnston, LLB, MBHL

### Biographies

**Moderator:** Josephine Johnston, LLB, MBHL

Biography: <https://www.thehastingscenter.org/team/johnston/>

**Panelist:** Krystal Tsosie, PhD, MPH, MA

Biography: <https://search.asu.edu/profile/535281>

**Panelist:** Phillip Wilcox, BForSci (Hons), PhD

Biography: <https://www.otago.ac.nz/maths-and-stats/people/otago0235749.html>

### ELSIhub Collections

ELSIhub Collections are essential reading lists on fundamental or emerging topics in ELSI, curated and explained by expert Collection Editors. Please use the links in the chat to access four collections related to this seminar.

ELSIhub Collections related to this seminar:

- Biocolonialism and Other “Western”-Centered Bioethical Failures Onto Indigenous Peoples by Krystal S. Tsosie, PhD, MPH, MA  
<https://elsihub.org/collection/biocolonialism-and-other-western-centered-bioethical-failures-indigenous-peoples>
- Technologies to Operationalize Indigenous Data Sovereignty by Māui Hudson, BHSc, AIT, MHSc, AUT & Stephanie Carroll, DrPH, MPH  
<https://elsihub.org/collection/technologies-operationalize-indigenous-data-sovereignty>



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- Realizing the Self-Determination Goals of Indigenous People in Genetics Research by Vanessa Y. Hiratsuka, PhD, MPH  
<https://elsihub.org/collection/realizing-self-determination-goals-indigenous-people-genetics-research>
- Game of Bones: Power, Ethics, and Emerging Technology in Paleogenomics Research by Keolu Fox, PhD  
<https://elsihub.org/collection/game-bones-power-ethics-and-emerging-technology-paleogenomics-research>

**Krystal Tsosie, PhD, MPH, MA & Phillip Wilcox, BForSci (Hons), PhD**

Link to “Mixed Blood Indians, *Racial Construction in the Early South*” (2005):

<https://ugapress.org/book/9780820327310/mixed-blood-indians/>

Link to “Iwi Map Aotearoa”: <https://malesurvivor.nz/kia-marire/resources/iwi-map-aotearoa/>

Link to “Whakapapa”: <https://maori.com/whakapapa/whakpap2.htm>

Link to “Aotearoa New Zealand genomic variome”:

<https://www.genomics-aotearoa.org.nz/our-work/health-projects/aotearoa-nz-genomic-variome>

Link to “Rakeiora: A pathfinder for genomic medicine in Aotearoa/New Zealand”:

<https://www.genomics-aotearoa.org.nz/our-work/health-projects/rakeiora-pathfinder-genomic-medicine>

Link to “Genomic Possibilities”: <https://www.otago.ac.nz/hekitenga/2019/otago731081.html>

Link to “Rights, interests and expectations: Indigenous perspectives on unrestricted access to genomic data” (2020): <https://doi.org/10.1038/s41576-020-0228-x>



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Link to “About Us” Page: <https://www.nph.org.nz/about-us>

Link to “A more-inclusive genome project aims to capture all of human diversity” (2022):  
<https://www.nature.com/articles/d41586-022-00726-y>

Link to “We Have “Gifted” Enough: Indigenous Genomic Data Sovereignty in Precision Medicine” (2021): <https://doi.org/10.1080/15265161.2021.1891347>

Link to “The FAIR Guiding Principles for scientific data management and stewardship” (2016):  
<https://doi.org/10.1038/sdata.2016.18>

Link to “The CARE Principles for Indigenous Data Governance” (2020):  
<https://datascience.codata.org/articles/10.5334/dsj-2020-043/>

Link to “Indigenous people across the contiguous United States have lost 98.9% of their historical lands” (2021):  
<https://www.science.org/content/article/native-tribes-have-lost-99-their-land-united-states#:~:text=The%20researchers%20found%20that%20Indigenous,they%20report%20today%20in%20Science%20>

Link to “Bridging the Digital Divide in Native American Communities”:  
<https://policylab.rutgers.edu/bridging-the-digital-divide-in-native-american-communities/#:~:text=According%20to%20an%20American%20Indian,be%20less%20than%20'minimally%20acceptable>

Link to “Indigenous Data Science Education”: <http://indigidata.org/>

## **Additional Resources Shared in Chat and Post-Forum Discussion**

Link to “Qualitative study of comprehension of heritability in genomics studies among the Yoruba in Nigeria” (2020): <https://doi.org/10.1186/s12910-020-00567-2>



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Link to “IDEAS 2023”: <https://sols.asu.edu/ideas>

Link to “ASHG Documents and Apologizes for Past Harms of Human Genetics Research, Commits to Building an Equitable Future” (2023):  
<https://www.ashg.org/publications-news/press-releases/ashg-documents-and-apologizes-for-past-harms-of-human-genetics-research-commits-to-building-an-equitable-future/>