

Data for Whom? Intellectual Property, Biodiversity, and Indigenous Genomic Data Sovereignty



Krystal Tsosie

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Bio:

Krystal Tsosie (Diné/Navajo Nation), PhD, MPH, MA, is an Indigenous geneticist-bioethicist and Assistant Professor in the School of Life Sciences at Arizona State University. As an advocate for Indigenous genomic data sovereignty, she co-founded the first US Indigenous-led biobank, a 501c3 nonprofit research institution called the Native BioData Consortium.



Her research can be encapsulated in two main foci: Indigenous population genetics and bioethics. In particular, she focuses on bioethical engagement of Indigenous communities in genomics and data science to build trust. As a whole, her interest is in integrating genomic and data approaches to assess Indigenous variation contributing to health inequities.

Beckett Sterner

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Bio: The driving question for my research is: what knowledge do we need to work together while differing in fundamental ways? Urgent global challenges such as biodiversity loss or climate change depend on research and decision-making processes that are highly decentralized yet must be coordinated worldwide and moreover frequently operate under incompatible or changing assumptions. Computational methods and infrastructure have become essential mediators in this regard by helping data travel across different temporal and spatial scales while preserving their relevance to the needs of people working in local, national, and international settings. Nonetheless, it is difficult to determine which approaches to data-intensive science and its knowledge infrastructure are best suited to bridging our differences without collapsing into overwhelming chaos or fragmentation. My research studies how and why pluralism— i.e. advancing multiple approaches to an issue— makes a difference to current and historical practices of computational science. I apply these insights to develop novel, collaborative approaches to making data and models relevant to global societal challenges.