



ELSI FRIDAY FORUM

Genomics and Data Sovereignty: Policy and Deliberative Approaches for Engaging Indigenous Communities

Date and time: Friday, May 14, 9am PT / 12pm ET

Speakers: Stephanie Russo Carroll and Justin Lund

Moderator: Nanibaa' Garrison

ELSIhub Collections

Realizing the Self-Determination Goals of Indigenous People in Genetics Research, curated by Vanessa Y. Hiratsuka, PhD, MPH, Co-Director of Research and Evaluation, Assistant Professor of Clinical and Translational Research, Center for Human Development, University of Alaska Anchorage

<https://elsihub.org/index.php/collection/realizing-self-determination-goals-indigenous-people-genetics-research>

Game of Bones: Power, Ethics, and Emerging Technology in Paleogenomics Research, curated by Keolu Fox, PhD, Assistant Professor, University of California, San Diego, Co-founder, Indigenous Futures Institute (IFI), Co-founder Native BioData Consortium (NBDC).

<https://elsihub.org/index.php/collection/game-bones-power-ethics-and-emerging-technology-paleogenomics-research>

Biography

Stephanie Russo Carroll, DrPH, MPH

Biography: <https://nni.arizona.edu/people/staff/leadership/stephanie-russo-carroll>

Justin Lund, MA

Biography: https://faculty.utah.edu/u0204259-Erin_Rothwell_PhD/hm/index.html

Moderator: Nanibaa' Garrison, PhD

Biography: <https://elsihub.org/directory/nanibaa-garrison>

Stephanie Russo Carroll, DrPH, MPH

For more info on the United States Indigenous Data Sovereignty Network, see:

<https://usindigenousdata.org/>



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For more info on the British Columbia First Nations' Data Governance Initiative (BCFNDGI), see: <https://www.bcfndgi.com/>

For more info on the Global Indigenous Data Alliance, see: <https://www.gida-global.org/>

Link to Kukutai and Taylor (2016):

<https://press-files.anu.edu.au/downloads/press/n2140/pdf/book.pdf?referer=2140>.

Link to Carroll et al (2019): <http://doi.org/10.5334/dsj-2019-031>

Carroll, S. R., Garba, I., Figueroa-Rodríguez, O. L., Holbrook, J., Lovett, R., Materechera, S., Parsons, M., Raseroka, K., Rodriguez-Lonebear, D., Rowe, R., Sara, R., Walker, J. D., Anderson, J., & Hudson, M. (2020). The CARE Principles for Indigenous Data Governance. *Data Science Journal*, 19(1), 43. <https://elsihub.org/publication/care-principles-indigenous-data-governance>

Carroll, S. R., Hudson, M., Holbrook, J., Materechera, S., & Anderson, J. (2020, November 9). Working with the CARE Principles: Operationalizing Indigenous Data Governance. *Ada Lovelace Institute*.

<https://www.adalovelaceinstitute.org/blog/care-principles-operationalising-indigenous-data-governance/>

Carroll, S. R., Herczog, E., Hudson, M., Russell, K., & Stall, S. (2021). Operationalizing the CARE and FAIR Principles for Indigenous data futures. *Scientific Data*, 8, 1-6.

<https://elsihub.org/publication/operationalizing-care-and-fair-principles-indigenous-data-future>

Garrison, N. A., Hudson, M., Ballantyne, L. L., Garba, I., Martinez, A., Tualii, M., Arbour, L., Caron, N. R., & Carroll, S. R. (2019). Genomic Research through an Indigenous Lens: Understanding the Expectations. *Annual Review of Genomics and Human Genetics*, 20, 495-517. <https://elsihub.org/publication/genomic-research-through-indigenous-lens-understanding-expectations>

Hudson, M., Garrison, N.A., Sterling, R. *et al.* (2020) Rights, interests and expectations: Indigenous perspectives on unrestricted access to genomic data. *Nature Review Genetics*, 21, 377-384.

<https://elsihub.org/publication/rights-interests-and-expectations-indigenous-perspectives-unrestricted-access-genomic>



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For more info on the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research, see: <https://aiatsis.gov.au/research/ethical-research>

Justin Lund, MA

For more info on the Center for the Ethics of Indigenous Genomics Research, see: <https://ou.edu/cas/anthropology/ceigr>

For more info on the Chickasaw Nation, see: <https://chickasaw.net/>

For more info on Southcentral Foundation, see: <https://www.southcentralfoundation.com/>

For more info on Missouri Breaks Industries Research, Inc., see: <https://www.missouri-breaks.com/>

Link to Israel et al (1998): <https://doi.org/10.1146/annurev.publhealth.19.1.173>

CEIGR Deliberation manuscripts:

Hiratsuka, V. Y., Beans, J. A., Blanchard, J. W., Reedy, J., Blacksher, J., Lund, J. R., & Spicer, P. G. (2020) An Alaska Native community's views on genetic research, testing, and return of results: Results from a public deliberation. *PLoS ONE*, 15(3), 1-16.

<https://elsihub.org/index.php/publication/alaska-native-communitys-views-genetic-research-testing-and-return-results-results>

Reedy, J., Blanchard, J. W., Lund, J., Spicer, P. G., Byars, C., Percy, M., Saunkeah, B., & Blacksher, E. Deliberations about genomic research and biobanks with citizens of the Chickasaw Nation. *Frontiers in Genetics*, 11(466), 1-6.

<https://elsihub.org/publication/deliberations-about-genomic-research-and-biobanks-citizens-chickasaw-nation>

The Center for the Ethics of Indigenous Genomic Research manuscripts:

Hiratsuka, V. Y., Beans, J. A., Reedy, J., Yracheta, J. M., Percy, M. T., Saunkeah, B., Woodbury, R. B., O'Leary, M., & Spicer, P. G. (2020). Fostering ethical, legal, and social implications research in tribal communities: The Center for the Ethics of Indigenous Genomic Research. *Journal of Empirical Research on Human Research Ethics*, 15(4), 271-278.

<https://elsihub.org/publication/fostering-ethical-legal-and-social-implications-research-tribal-communities-center-0>



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Blanchard, J., Hiratsuka, V., Beans, J. A., Lund, J., Saunkeah, B., Yracheta, J., Woodbury, B., Blacksher, E., Peercy, M., Ketchum, S., Byars, C., & Spicer, P. (2020). Power sharing, capacity building, and evolving roles in ELSI: The Center for the Ethics of Indigenous Genomic Research. *Collaborations: A Journal of Community-based Research and Practice*, 3(1), 18. <https://elsihub.org/publication/power-sharing-capacity-building-and-evolving-roles-elsi-center-et-hics-indigenous>