



ELSI FRIDAY FORUM

Genomic Data Sharing: Putting Principles and Policy into Practice

Date and time: Friday, October 8, 9am PT/12pm ET

Speakers: Heidi Rehm and Keolu Fox

Moderator: Malia Fullerton

Biography

Moderator: Malia Fullerton, PhD

<https://elsihub.org/directory/stephanie-m-fullerton>

Panelist: Heidi Rehm, PhD

<https://elsihub.org/directory/heidi-l-rehm>

Panelist: Keolu Fox, PhD

Biography: <https://elsihub.org/directory/keolu-fox>

Please use the link to access **Technologies to Operationalize Indigenous Data Sovereignty**, curated by Māui Hudson, BHSc, AIT, MHSc, AUT, Associate Professor and Director, Te Kotahi Research Institute, University of Waikato, and Stephanie Russo Carroll, DrPH, MPH, Assistant Professor, Public Health, and Associate Director, Native Nations Institute, University of Arizona. <https://elsihub.org/collection/technologies-operationalize-indigenous-data-sovereignty>

Heidi Rehm, PhD

Link to lab website: <https://the-tgg.org/>

Link to Twitter: <https://twitter.com/heidirehm>

Link to Philippakis et al. (2015): <https://doi.org/10.1002/humu.22858>

Link to Buske et al. (2015): <https://doi.org/10.1002/humu.22850>

Link to Dyke et al. (2017): <https://doi.org/10.1002/humu.23278>



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For more information on ClinVar, visit: <https://www.ncbi.nlm.nih.gov/clinvar/>

Link to Azzariti et al. (2018): <https://dx.doi.org/10.1101%2Fmcs.a002345>

Link to Wright et al. (2019): <https://doi.org/10.12688/wellcomeopenres.15090.1>

Link to ClinGen's Clinical Broad Data Sharing Consent Videos:
<https://www.clinicalgenome.org/tools/consent-resources/videos/>

Link to UK position statement: <https://doi.org/10.12688/wellcomeopenres.15090.1>

Link to ClinGen "Consent to Share Genetic and Health Information" document:
https://www.clinicalgenome.org/site/assets/files/3089/clingen_consent_-_final_4_6_17.pdf

Link to slide deck:
<https://docs.google.com/presentation/d/1Bly61St22OUslZj6GNdRutKgIhX3md8H/edit?usp=sharing&oid=104875469303474370846&rtpof=true&sd=true>

Keolu Fox, PhD

Link to lab website: <https://ifi.ucsd.edu/>

Link to Twitter: <https://twitter.com/keolufox>

Link to Data is Power:
<https://www.foreignaffairs.com/articles/united-states/2021-04-16/data-power-new-rules-digital-age>

Link to Hudson et al. (2020): <https://www.nature.com/articles/s41576-020-0228-x>

Link to Claw et al. (2018): <https://www.nature.com/articles/s41467-018-05188-3>

Link to Native BioData Consortium (NBDC): <https://nativebio.org/>

Link to Indigidata: <https://indigidata.nativebio.org/>



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Link to Experiment Challenges - Indigenous Futures: <https://experiment.com/grants/if>

Discussion

Link to Tsosie et al. (2019): <https://www.nature.com/articles/s41576-019-0161-z>

Link to All of Us Tribal Engagement:

<https://allofus.nih.gov/about/diversity-and-inclusion/all-us-tribal-engagement>

MacArthur Foundation Award

[https://www.macfound.org/press/press-releases/macarthur-awards-\\$80-million-to-advance-racial-and-ethnic-justice](https://www.macfound.org/press/press-releases/macarthur-awards-$80-million-to-advance-racial-and-ethnic-justice)

Traditional and Biocultural Labels and Notices <https://localcontexts.org/>