

Series Title: ELSIcon2022 ELSIconversations

Session Title: Stakeholder Perspectives on Data Sharing and Privacy

Date: Tuesday, November 29, 2022 12-1 pm ET

Panelists: Karen Meagher, PhD; Alyx Vogle, MS, CGC; & LaKisha David, MCP, PhD

Moderators: Vasiliki N. Rahimzadeh, PhD; Sara Ackerman, PhD, MPH; & Sandra Soo-Jin Lee, PhD

Biographies

Panelist: Karen Meagher, PhD

Biography: <https://elsihub.org/directory/karen-m-meagher>

Panelist: Alyx Vogle, MS, CGC

Biography: <https://www.mghihp.edu/alyx-vogle-ms-cgc>

Panelist: LaKisha David, MCP, PhD

Biography: <https://medicalethicshealthpolicy.med.upenn.edu/fellows-2017/lakisha-davi>

Moderator: Vasiliki N. Rahimzadeh, PhD, MSc

Biography: <https://elsihub.org/directory/vasiliki-rahimzadeh>

Moderator: Sara Ackerman, PhD, MPH

Biography: <https://elsihub.org/directory/sara-l-ackerman>

Moderator: Sandra Soo-Jin Lee, PhD

Biography: <https://elsihub.org/directory/sandra-soo-jin-lee>

Karen Meagher, PhD

Link to Meagher (2022): <https://doi.org/10.3390/jpm12081308>

Link to ELSI and the New Precision Stewards?:

<https://elsihub.org/video/elsi-and-new-precision-stewards>

Link to Sharp and Meagher (2022):

https://www.mdpi.com/journal/jpm/special_issues/ethics_precision

Link to Frid-Nielsen (2019): <https://doi.org/10.1016/j.socscimed.2019.112596>

Alyx Vogle, MS, CGC

Link to INSIGHT @ Work: An Interdisciplinary Study on the Ethical, Legal and Social, Implications (ELSI) of Voluntary Workplace Genomic Testing (wGT):
<https://elsihub.org/video/insight-work-interdisciplinary-study-ethical-legal-and-social-implications-elsi-voluntary>

LaKisha David, MCP, PhD

Link to NIH Research Areas and Sample Topics:
<https://www.genome.gov/Funded-Programs-Projects/ELSI-Research-Program/research-areas#conceptions>

Link to An Exploration of Family Connection and African Ethnic Identity Development Among African Americans Finding African Genetic Relatives While Using Consumer Genetic Genealogy Services:
<https://elsihub.org/video/exploration-family-connection-and-african-ethnic-identity-development-among-african-americans>

Audience Q&A

Link to Prainsack and Forgó (2022): <https://doi.org/10.1038/s41591-022-01955-4>

Link to Mackey et al (2022): <https://doi.org/10.1016/j.cell.2022.06.030>

Link to WHO's Pandemic Influenza Preparedness Framework:
<https://www.who.int/publications/i/item/9789240024854>

Link to Martin (1995):
<https://www.penguinrandomhouse.com/books/204348/flexible-bodies-by-emily-martin/>