ELSI FRIDAY FORUM

Biobanking in the Era of COVID

Date and time: Friday, January 8th 9am PT/ 12pm ET Speakers: Sara Chandross Hull and Kyle Brothers Moderator: Aaron Goldenberg

Biography Kyle Brothers, MD, PhD

Biography: https://louisville.edu/bioethics/directory/kyle-brothers-m.d

Kyle Brothers – Dr. Brothers is an Associate Professor of Pediatrics and the Endowed Chair for Pediatric Clinical and Translational Research at the University of Louisville, where he directs the Division of Pediatric Clinical and Translational Research and is a member of the Institute for Bioethics, Health Policy, and Law. Dr. Brothers is a pediatrician and bioethicist who conducts research on ethical issues in the translation of genomic technologies to clinical practice, and research ethics issues encountered in contemporary models of biomedical research.

Sara Hull, PhD

Biography: <u>https://www.bioethics.nih.gov/people/hull-bio.shtml</u>

Sara Hull – Dr. Hull directs the Bioethics Core of the National Human Genome Research Institute (NHGRI) at the NIH, which provides bioethics education, consultation, and administrative support to investigators in the Intramural research program. Dr. Hull also serves as a Chair of the NIH Intramural Institutional Review Board and is on the faculty of the NIH Clinical Center's Department of Bioethics, where her research and capacity building interests focus primarily on the intersections between research ethics and genomic research. We are also fortunate to have a number of colleagues who have been working with Kyle, Sara,

and myself who will be on hand during our discussion today and will be able to add to our conversation, including Benjamin Berkman from the NIH Department of Bioethics, and Jean Cadigan from the Department of Social Medicine at the University of North Carolina-Chapel Hill.

Resources

Fink, S., & Baker, M. (2020, March 11). 'It's Just Everywhere Already': How Delays in Testing Set Back the U.S. Coronavirus Response. The New York Times. https://www.nytimes.com/2020/03/10/us/coronavirus-testing-delays.html

Chu, H. Y., Englund, J. A., Starita, L. M., Famulare, M., Brandstetter, E., Nickerson, D. A., Rieder, M. J., Adler, A., Lacombe, K., Kim, A. E., Graham, C., Logue, J., Wolf, C. R., Heimonen, J., McCulloch, D. J., Han, P. D., Sibley, T. R., Lee, J., Ilcisin, M., ... Bedford, T. (2020). Early Detection of Covid-19 through a Citywide Pandemic Surveillance Platform. New England Journal of Medicine, 383(2), 185–187. https://doi.org/10.1056/NEJMc2008646

The Oxford Handbook of Public Health Ethics. (2019). In A. Mastroianni, J. Kahn, & N. Kass (Eds.), The Oxford Handbook of Public Health Ethics. Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190245191.001.0001

- o Taylor, H. A., "Framing Public Health Research Ethics," 331-341
- o Lee, L. M., "Public Health Surveillance: Ethical Considerations," 320-330
- o Smith, M. and R. Upshur, "Pandemic Disease, Public Health, and Ethics," 797-811

National Institutes of Health, "Post-Consultation Decision: American Indian and Alaska Native (AI/AN) Inclusion in the All of Us Research Program COVID-19 Serology Study," <u>https://dpcpsi.nih.gov/sites/default/files/All of Us Decision Brief 508.pdf</u>

Wendler, D., & Berkman, B. E. (2020). Maximizing the value of human biospecimens: Lessons from coronavirus and the Seattle flu study. American Journal of Medical Genetics. Part a. https://doi.org/10.1002/ajmg.a.61891

Largent, E. A., Halpern, S. D., & Lynch, H. F. (2020). Waivers and Alterations of Research Informed Consent During the COVID-19 Pandemic. Annals of Internal Medicine. <u>https://doi.org/10.7326/M20-6993</u>