

UNIVERSITY OF MIAMI  
MILLER SCHOOL OF MEDICINE

INSTITUTE for BIOETHICS  
& HEALTH POLICY



## 30TH ANNUAL SERIES

# DIALOGUES IN RESEARCH ETHICS

Monthly Conference Series *Dialogue No.201*

**Friday, October 15, 2021, 12:00 – 1:00 p.m.**

Meeting ID: 949 5203 8412 | Passcode: 593225

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### Data Mobility and HIPAA:

### Protect Privacy and Support Research

Alda Yuan, JD, *Washington, D.C.*

The data mobility issues which exacerbated the Covid-19 crisis lay bare the acute need for a health data privacy regime able to protect patients while enabling beneficial aggregation. The existing health data privacy framework is misaligned with reality because it assumes that health data is analogous to physical records, can be governed like property, and can be protected through procedural safeguards that cease to function once data has been “released.” That is, the law understands health data as either protected and immobile or, once released, mobile and unprotected. To build a health data privacy system that supports both data sharing as well as lasting protection for patients, the nation must shift toward a rights-based framework in which health data is recognized as a manifestation of personhood.

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**Alda Yuan** is an attorney who has written at the intersection of bioethics, health data privacy, and human subjects research. She is a graduate of Yale Law School and has worked to develop the Research Data Framework with the National Institute of Standards and Technology as well as a Public Health Analyst in the Office of the National Coordinator (ONC) for Health Information Technology, the principal federal entity charged with coordination of nationwide efforts to implement and use advanced health information technology and the electronic exchange of health information.

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