SESSION II: PROTECTION OF PRIVACY

Session Objective:

• The purpose of the session was to explore potential best practices to address data privacy and security, consent and data governance in cloud-based neuroscience research.

• Discussants:
  Kristen Rosati, Coppersmith Brockelman/Past President American Health Lawyers Association – “Web of Laws” – EU, US/State
  William Hanson, University of Pennsylvania/CMIO – Penn Case Study and Principles for Data Access, Use & Disclosure
  Clare Mackay, University of Oxford/Translational Imaging and Infrastructure – Provided a perspective from the UK – Wellcome/DPUK and UK Biobank
Web of Laws

New landscape of regulations:
• GDPR effective May 2018
• Common Rule revisions effective January 2019
• Changing U.S. state laws - California Consumer Protection Act & other states following

Changing standards of ”de-identification”
• HIPAA versus GDPR (safe harbor)
• Common Rule standards for identifiability may change
Changing standards of “risk” with re-identification

- Nature (Rocher et al 2019) - estimating the success of re-identifications in incomplete datasets using generative models
  - 99.98% of Americans would be correctly re-identified in any dataset using 15 demographic attributes.

- What is the “risk” with re-identification
  - Within U.S. - implications for insurance (medical, life), employment, national security, etc.

- Currently there are NO Federal laws that prohibits re-identification of individuals
Penn Case Study

• Established principles for Access, Use and Disclosure
  – Lawful basis
  – Institutional Mission & Values
  – Trustworthiness & Accountability
  – Risk Mitigation
  – Strong Secure Controls
  – Documentation

• A proposal made for a WG to pull together multiple institutions and generate best practices:
  – Consent templates
  – Governance principles
  – Definitions of “sensitive data” or “qualified researcher”

• JAMA Position Paper on Data Governance
Perspective from the UK

• 3 different governance models:
  – UK Biobank (single IRB, consent process)
  – Wellcome - hybrid
  – DPUK - multiple institutions, multiple IRBs, consents

• Broad concerns about placing data in the cloud → Centralized infrastructures, controlled access, no downloading can be more protective

• Perspective of Participants
  – Privacy & security yes, but... informed for a purpose

  RISK ↔ BENEFIT is the Point
Additional points

• Who should have access to datasets?
• Federated data - common data model?
• ROW access - authentication?
• Academic institutional resources to support data-sharing and governance
• Self-Help Group/Community to serve as a resource for use cases