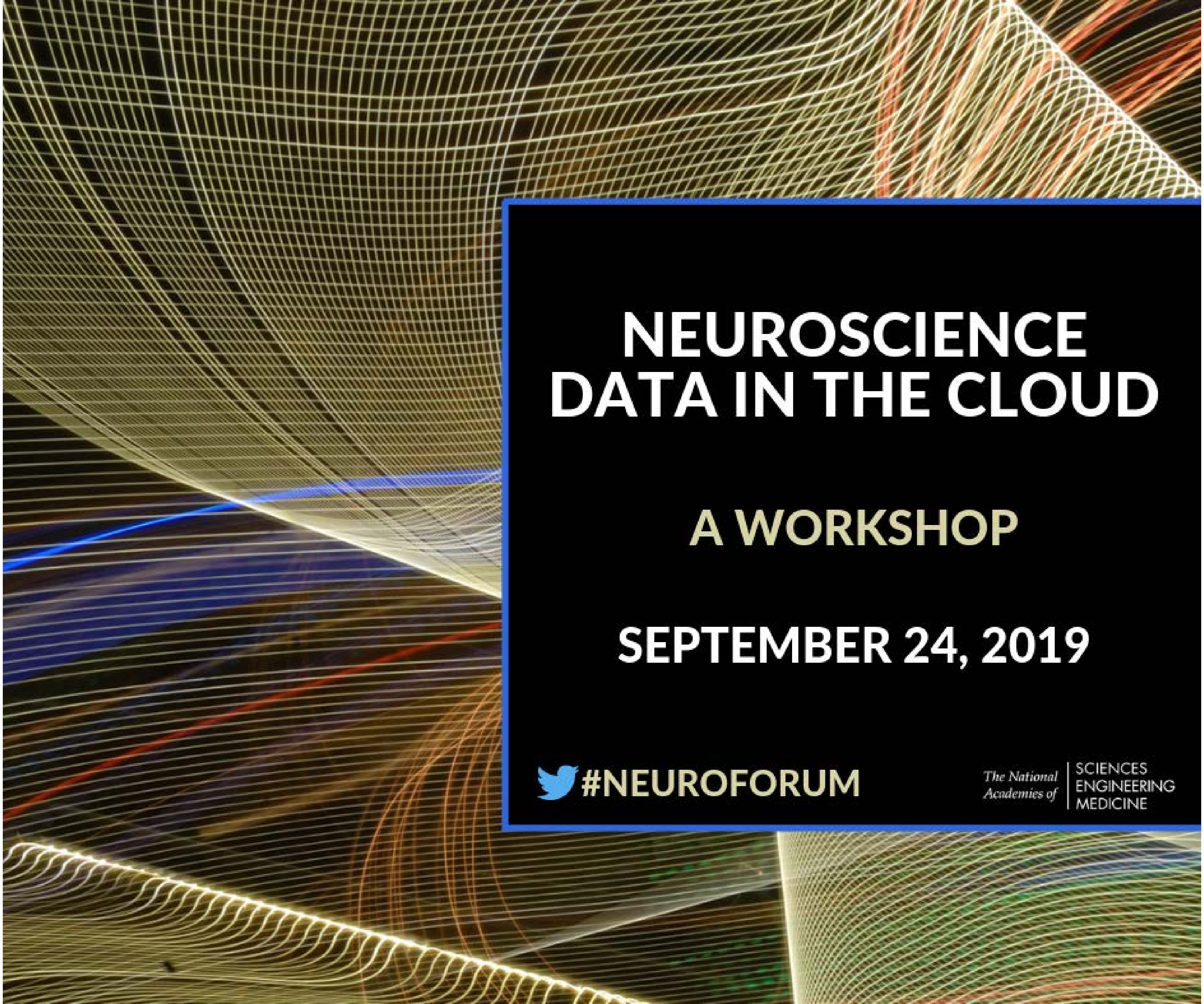

NEUROSCIENCE DATA IN THE CLOUD

A WORKSHOP

SEPTEMBER 24, 2019

#NEUROFORUM

The National Academies of SCIENCES ENGINEERING MEDICINE

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

Web of Laws

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 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