Brain Research Through Advancing Innovative Neurotechnologies® (BRAIN)
Workshop on Ethics of Sharing Human Brain Data Collected in Biomedical Research
Part 1 Agenda – Monday, July 17, 2023
Times are ET - Open to the Public

DAY 1

10:00 AM   **Welcome –** *John Ngai*

10:05 AM   **Introduction and background –** *Saskia Hendriks*

10:30 AM   **Panel 1: The data that is collected and stored by neurotechnologies and the inferences that can be made from these data**

Speakers will discuss the inferences that can be drawn from shared data that are collected through neurotechnologies regularly used in BRAIN-funded studies with human participants. Speakers will cover functional magnetic resonance imaging (fMRI), electroencephalography (EEG), deep brain stimulation (DBS), structural brain imaging, and brain-computer interfaces (BCI).

- Susie Huang, MD, PhD, Associate Professor of Radiology, Harvard Medical School
- Lorna Quandt, PhD, Associate Professor of Educational Neuroscience, Gallaudet University
- Douglas Greve, PhD, Assistant Professor of Radiology, Harvard Medical School
- Jennifer Collinger, PhD, Associate Professor of Physical Medicine and Rehabilitation, University of Pittsburgh
- Doris Wang, MD, PhD, Associate Professor of Neurosurgery, University of California at San Francisco

12:30 PM   **Panel 1 Discussion (moderators: Sameer Sheth and Nina Hsu)**

1:00 PM   **LUNCH/BREAK**

2:00 PM   **Panel 2: Inferences to be drawn from data and their implications for data sharing**

Speakers will discuss the inferences that can be drawn from shared data across technologies, including combining data types and collecting data through from implanted neurotechnologies. Furthermore, implications of the ability to decode semantic representations and effects of racially exclusionary practices in collecting and managing brain data on data sharing will be discussed.

- Conor Russomanno, Founder and CEO, OpenBCI
- Alexander Huth, PhD, Assistant Professor of Neuroscience, University of Texas at Austin
- Michael Young, MD, Associate Director, NeuroRecovery Clinic, Massachusetts General Hospital

3:00 PM	**Panel 2 Discussion (moderators: Jim Eberwine and Saskia Hendriks)**
3:30 PM	**BREAK**
3:45 PM	**Panel 3: The potential risks to communities**

Speakers will discuss potential risks that can arise from sharing human brain data, including potential risks to communities.

- o <u>Jocelyn Ricard</u>, Graduate Student, Stanford University
- o <u>Krystal Tsosie, PhD, MPH, MA</u>, Assistant Professor in the School of Life Sciences, Arizona State University

4:25 PM	**Panel 3 Discussion (moderators Nita Farahany and Saskia Hendriks)**
4:45 PM	**Day 1 wrap up**
5:00 PM	**Adjourn**

Brain Research Through Advancing Innovative Neurotechnologies® (BRAIN)
Workshop on Ethics of Sharing Human Brain Data Collected in Biomedical Research
Part 2 Agenda – Tuesday, July 18, 2023
Times are ET – Open to the Public

DAY 2

10:00 AM	**Welcome -** *John Ngai*
10:05 AM	**Recap of Day 1**
10:20 AM	**Panel 4: The potential risks to individuals of sharing different types of human brain data**

Speakers will discuss potential risks that can arise from sharing human brain data, including re-identification and other potential risks to individuals.

- o Russell Poldrack, PhD, Professor of Psychology, Stanford University
- o Sara Berger, PhD, Senior Research Scientist, IBM

11:00 AM	**Panel 4 Discussion (moderators: Syd Johnson and Saskia Hendriks)**
11:30 AM	**BREAK**
11:45 AM	**Panel 5: Research participants' perspectives on sharing human brain data**

Speakers will discuss research participants' perspectives on sharing human brain data, including presentations from individuals with lived experience of participating in neuroscience studies, as well as empirical work on research participants' views on data sharing.

- o Nathan Copeland, Research participant
- o Christine Von Raesfeld, Founder and CEO of People with Empathy
- o Amy McGuire, JD, PhD, Leon Jaworski Professor of Biomedical Ethics and Director, Baylor College of Medicine

12:45 PM	**Panel 5 Discussion (moderators: Christine Grady and Nina Hsu)**
1:15 PM	**LUNCH/BREAK**
2:15 PM	**Breakout rooms/Small-group discussions**
3:15 PM	**Re-convene/breakout room report-outs**
4:00 PM	**Day 2 wrap up, next steps**
4:15 PM	**Adjourn**