Neuroscience Data in the Cloud—A Workshop

September 24, 2019
The Keck Center | Room 100
500 Fifth Street NW, Washington, DC 20001

Workshop Objectives:

This public workshop will convene stakeholders involved in cloud-based neuroscience initiatives and research. The workshop will explore the burgeoning use of cloud technology to advance neuroscience research and share approaches to addressing current barriers. Participants will include individuals from academia, government, foundations, pharmaceutical and information technology industries, and the legal system.

Invited presentations and discussions will be designed to:

- Review the landscape of major neuroscience cloud-based initiatives and other uses of cloud technology within neuroscience research.*
- Discuss aspirational goals for maximizing benefit from data and compute in the cloud by empowering broad and meaningful data sharing and fostering open science.
- Consider best practices and policies that would increase efficiencies within and across cloud resources, including around aspects such as:
  - Authorization by data sources for and accessibility to a variety of data types by a variety of users
    - Resharing of derived data
    - Funding, sustainability, and governance
  - Protection of privacy
    (Scope of distribution and type of data may affect the degree of privacy protection)
    - Regulatory compliance (HIPAA, Common Rule, FDA, etc.)
    - Consent to allow broad sharing and use of data
    - Data use agreements
  - Assignment of credit, ownership, and licensing
    - Ownership of data sources (participants, researchers, agencies)
    - Authorization for derivative uses
    - Acknowledgment of funding sources
    - Publication: scope and form of citation
  - Technical issues
    - Formatting standards (where they exist)
    - Validation standards (where they exist)
    - IT standards (communication and security protocols)
    - Archiving practices (types, locations, and parties responsible)
  - Researcher support and training
- Explore potential next steps to move the field forward to develop and deploy best practices in the service of achieving the aspirational goals.

*Please refer to the workshop briefing book for overviews of neuroscience cloud-based initiatives represented by workshop participants.

September 24, 2019

8:30 a.m. Welcome and opening remarks

> DEANNA BARCH, Washington University in St. Louis, *Workshop Co-chair*
>
> MICHAEL HUERTA, National Library of Medicine, National Institutes of Health, *Workshop Co-chair*

Session I: The Use of Cloud-Based Technology for Neuroscience Research – An Overview of Successes and Current Barriers

Objectives: Explore the range of neuroscience cloud-based initiatives and other uses of cloud technology within neuroscience research. Discuss current successes and barriers in the field.

8:40 a.m. Session overview

> ADAM FERGUSON, University of California, San Francisco

Harnessing the Power of Cloud Technology to Propel Neuroscience Research Forward

8:45 a.m. Speakers

> MARYANN MARTONE, University of California, San Diego; International Neuroinformatics Coordinating Facility
> RUSSELL POLDRACK (*via webcast*), Stanford University
> NICK WEBER, National Institutes of Health

9:30 a.m. General discussion with speakers

10:00 a.m. Introduction to breakout discussions

> *Workshop Co-chairs*

10:15 a.m. BREAK
Participants will go to their designated breakout group location as indicated on the meeting handouts.

Session II: Breakout Discussions

Objectives: In small groups, identify potential best practices and policies that will address current challenges to using cloud-based technologies to advance neuroscience research. Consider variations in best practices as a function of use case (i.e., basic versus clinical research in academia, commercial, and government settings). Discuss implications for researcher support and training.

10:30 a.m. Breakout Sessions

> **Protection of Privacy**
> Moderator: KRISTEN ROSATI, Coppersmith Brockelman PLC
> Rapporteur: MAGALI HAAS, Cohen Veterans Bioscience
> Discussants: C. WILLIAM HANSON III, University of Pennsylvania
> CLARE MACKAY, University of Oxford

Assignment of Credit, Ownership, and Licensing
Moderator: JONATHAN COHEN, Princeton University
Rapporteur & Discussant: LEA SHANLEY, University of Wisconsin-Madison
Discussants: CAROL HAMILTON, RTI International
SEAN HILL, CAMH

Data Management
Moderator: MICHAEL HAWRYLYCZ, Allen Institute for Brain Science
Rapporteur: MICHAEL HUERTA, National Library of Medicine
Discussants: DANIEL MARCUS, Washington University School of Medicine
RACHEL RAMONI, Department of Veterans Affairs
JANAINA MOURAO-MIRANDA, University College London

Platform Governance, Funding, and Sustainability
Moderator: GREGORY FARBER, National Institute of Mental Health
Rapporteur: ROSA CANET-AVILÉS, Foundation for the National Institutes of Health
Discussants: SEAN HORGAN, Verily
RUTH MARINSHAW, Stanford University
ANTHONY PHILIPPAKIS, Broad Institute of MIT and Harvard

12:00 p.m.   LUNCH
All participants reconvene in Keck 100 following lunch

1:00 p.m.   Report out from each breakout group (10-minutes each)
Breakout Session Moderators and Rapporteurs

1:40 p.m.   General discussion

2:10 p.m.   Overview of the afternoon breakout discussions
Workshop Co-chairs

2:15 p.m.   BREAK
Participants will go to their designated breakout group location as indicated on the meeting handouts.

2:30 p.m.   Breakout discussions
All participants reconvene in Keck 100 at 3:25p.m.

Clinical Trial and Research Data
Moderator: LEE LANCASHIRE, Cohen Veterans Bioscience
Rapporteur: DAVID ALONSO, The Michael J. Fox Foundation for Parkinson's Research
Discussants: LARA MANGRAVITE, Sage Bionetworks
REBECCA LI, Vivli

Genetic Data
Moderator: BENJAMIN NEALE, Massachusetts General Hospital; Broad Institute
Rapporteur & Discussant: ARPANA AGARWAL, Washington University in St. Louis
Discussant: MICHAEL NALLS, National Institute on Aging

Neuroimaging Data
Moderator: MICHAEL MILHAM, Child Mind Institute
Rapporteur: DEANNA BARCH, Washington University in St. Louis
Discussants: JESSICA TURNER, Georgia State University
        ALAN EVANS, McGill University

Real-World Data
Moderator: MARGARET SUTHERLAND, Chan Zuckerberg Initiative
Rapporteur: STUART HOFFMAN, Department of Veterans Affairs
Discussants: ADRIANA DI MARTINO, Child Mind Institute
        PETER WAHL, Optum

3:30 p.m.   Report out from each breakout group (10-minutes each)

         Breakout Session Moderators and Rapporteurs

4:10 p.m.   General discussion

Session III: Future Directions

Objective: Synthesize key highlights from the workshop discussions, including identifying next steps and promising areas for future action.

4:30 p.m.   Session Overview

         MAGALI HAAS, Cohen Veterans Bioscience

4:35 p.m.   Moving the field forward: Reflections on tangible next steps (5-minutes each)

         Lightning round of comments from a diverse group of panelists across multiple sectors (e.g., academia, government, industry, and nonprofits), including:

                TED WILLKE, Intel Labs; Portland State University
                DOUGLAS LANDSMAN, National Multiple Sclerosis Society
                SILVANA BORGES, Food and Drug Administration

4:50 p.m.   General discussion

5:25 p.m.   Synthesis of workshop themes and future directions

         DEANNA BARCH, Washington University in St. Louis, *Workshop Co-chair*

         MICHAEL HUERTA, National Library of Medicine, National Institutes of Health, *Workshop Co-chair*

5:30 p.m.   ADJOURN WORKSHOP

Workshop Planning Committee

Deanna Barch (Co-Chair), Washington University in St. Louis
Michael Huerta (Co-Chair), National Library of Medicine, National Institutes of Health
Amiee Aloi, Gates Ventures
Rosa Canet-Avilés, Foundation for the National Institutes of Health
Jonathan Cohen, Princeton University
Patrick Cullinan, Takeda
Greg Farber, National Institute of Mental Health
Daniel Geschwind, University of California, Los Angeles
Magali Haas, Cohen Veterans Bioscience
Michael Hawrylycz, Allen Institute for Brain Science
Stuart Hoffman, Department of Veterans Affairs
Michael Milham, Child Mind Institute
Karla Miller, University of Oxford
Benjamin Neale, Massachusetts General Hospital; Broad Institute
Kristen Rosati, Coppersmith Brockelman PLC
Luba Smolensky, The Michael J. Fox Foundation for Parkinson's Research
Margaret Sutherland, Chan Zuckerberg Initiative