

February 2019 Meeting of the BRAIN Initiative Neuroethics Working Group

On February 11, 2019, the National Institutes of Health (NIH) Brain Research through Advancing Innovative Neurotechnologies® (BRAIN) Initiative convened a meeting of the Neuroethics Working Group in Bethesda, Maryland. Participants at the meeting discussed the current state of the BRAIN Initiative and ethical considerations for the sharing of brain research data.

Dr. Walter Koroshetz, Director of the National Institute of Neurological Disorders and Stroke (NINDS) and co-leader of the NIH BRAIN Initiative, opened the workshop by providing an update on the progress made during the first phase of the Initiative, including assessments of the seven priority areas identified by [BRAIN 2025, the NIH BRAIN Initiative's](#) roadmap. In June, a working group of the Advisory Committee to the NIH Director will complete an update of *BRAIN 2025* to guide the second phase of the initiative. This phase is scheduled to run through 2026.

The new technologies generated by the BRAIN Initiative raise important ethical implications, including questions surrounding data sharing. Four questions were posed to prime the discussion:

1. What is the right balance between providing data access and protecting patient privacy and data security?
2. What is the appropriate approach to ensure informed consent provisions are matched with researcher access permissions?
3. What are the ethical considerations when performing secondary analyses on existing data (e.g., extracting information via artificial intelligence)?
4. How can we incentivize the scientific community to do more than simply share data (i.e., organize, annotate, and help make the data more usable)?

Hank Greeley, J.D. began by describing two axes of data sharing that are applicable to BRAIN Initiative projects:

1. The sharing of data between scientists, particularly between scientists who generated the data and other scientists who would like access to data they didn't generate.
2. Data from human studies are about individual people, who may have different ideas about what personal data should be shared.

Further, projects funded by the BRAIN Initiative are generating large amounts of data, and brain data may shed light on individuals' thought processes and identities.

Data Sharing Between Scientists

NIH representatives discussed the importance of responsible data stewardship, especially in the context of the BRAIN Initiative Data Sharing Infrastructure, which currently includes three FOAs for projects dedicated to establishing [data archives](#), [data standards](#), and to develop [data integration and analysis tools](#).

Science is becoming increasingly digital, and researchers today can generate vast amounts of data quickly. This means that new tools must be developed to facilitate the sharing of data and just as importantly, the use of that shared data. It is also important to consider when it is appropriate for patients/participants to have access to their own data (i.e., who owns/controls the data being

collected?). An additional consideration is whether “citizen scientists” (i.e., members of the public) should have access to data in some cases.

Arthur Toga, Ph.D. from the University of Southern California described three different platforms that have been developed for neural data sharing purposes: [ENIGMA](#), [GAAIN](#), and [DABI \(Data Archive for the BRAIN Initiative\)](#) and shared some lessons learned. Each set of data comes with its own set of requirements and issues, and it is crucial to be proactive when developing a data-sharing framework to maximize the ability to share and use data.

Sharing Data About Individuals and Their Perspectives on Data Sharing

A second important issue discussed in the meeting surrounded the ethics of sharing personal data, including health records, for research purposes, including issues around informed consent. The Health Insurance Portability and Accountability Act (HIPAA) was discussed by Mark Rothstein, J.D. as providing relatively limited protection to patient information, as it was never intended to support comprehensive health privacy.

Dr. Nita Farahany, J.D. Ph.D. presented the results of her study looking at the public’s perceptions of brain privacy. Her findings show that people remain more concerned about information such as their social security number than information about their brains (e.g., thought patterns, brains scans, etc.). Digging deeper, her data suggest this could be because people don’t appreciate the risks associated with potential misuse of brain data.

The group agreed that data sharing is necessary, but that there could be types of brain data that should not be shared. In addition, it is important to understand peoples’ motivations for participating in research and what their expectations are around privacy. The term “precision privacy” was brought up to emphasize that each individual’s expectations are likely to be different, so a “one-size-fits-all” approach could be problematic.

Additional Updates

Following the discussion of data sharing, various round table group updates were provided.

Neuroethics Working Group members contributed to a [special issue of *Neuron*](#) published on February 6, 2019, that is focused on neuroethics. The issue includes seven papers, each from an existing or emerging large-scale brain research project, including the NIH BRAIN Initiative.

Dr. Koroshetz stressed the need for increased public outreach regarding the BRAIN Initiative and the importance of public education about the progress being made now and in the future, and the ethical issues being discussed.

The International Neuroethics Society will have its annual meeting October 17-18, 2019, immediately before the Society for Neuroscience meeting.

The [Neuroethics Guiding Principles for the NIH BRAIN Initiative](#) paper was published in December 2018 in the *Journal of Neuroscience* along with a [commentary](#) from the NIH Institute and Center directors participating in the BRAIN Initiative.

The meeting concluded with a closed session of the Neuroethics Working Group and federal staff.