

**Brain Research through Advancing Innovative Neurotechnologies® (BRAIN)
Neuroethics Working Group (NEWG) Meeting
August 19th, 2019**

On August 19, 2019, the National Institutes of Health (NIH) Brain Research through Advancing Innovative Neurotechnologies® (BRAIN) Initiative convened a meeting of the [Neuroethics Working Group \(NEWG\)](#) in Bethesda, Maryland. Participants at the meeting discussed the current state of the BRAIN Initiative, ways to improve communication about neuroethics and other scientific issues, and provided updates on four BRAIN- funded projects on neuroethics.

The meeting began with a closed session of the NEWG and federal staff.

To begin the open session of the meeting, Dr. Walter Koroshetz, Director of the National Institute of Neurological Disorders and Stroke (NINDS) and co-leader of the NIH BRAIN Initiative, provided an update on the current status of the BRAIN Initiative, including updates on the planning of the second phase of the Initiative, dubbed BRAIN 2.0.

A working group for BRAIN 2.0 of the Advisory Committee to the NIH Director (ACD) reviewed the scientific progress thus far of BRAIN in order to provide input on its strategic plan, while the BRAIN Neuroethics Subgroup (BNS) was charged with developing a Neuroethics Roadmap for the NIH BRAIN Initiative. These documents were presented to the ACD on June 14, and the reports are currently being finalized with NIH staff based on feedback received at these meetings. The reports and the recordings of presentations made at these meetings are available at <https://acd.od.nih.gov/meetings.html>. The presentation from Dr. Koroshetz concluded with a discussion of recent BRAIN-funded studies with potential ethical implications regarding the use of human subjects and brain recordings from those patients, including a [recent Nature paper](#) by [Edward Chang's lab](#). The study described the synthesis of speech from recordings obtained from epilepsy patients undergoing surgery. NEWG member Dr. Nita Farahany commented that some members of the public have reacted to this study suggesting that it involves “mind reading”, when in fact the study demonstrates some ability to decode spoken or mimed speech based on patterns of neural signals that control speech production. The ensuing discussion pointed to a potential role for NEWG when presenting studies with interesting neuroethical implications to the public via press releases or other forms of communication. The development of fact sheets for the media on similar topics was also discussed.

Strategic Science Communication: A Social Scientific Approach to Public Engagement

[John Besley](#), PhD from Michigan State University, presented a talk covering his research on how scientists communicate to the public and what their goals are for such communications. Dr. Besley also discussed various tactics and channels used in public communications, with an over-arching message that strategic communication should be driven by goals. For example, scientists may want people with whom they are communicating to believe that scientists are the type of people who are willing to listen. Dr. Besley also gave an example of diving deep into a scenario of science communication aimed at decreasing public misunderstandings, asking: Why do you want to decrease misunderstandings, and what do you think will happen if this succeeds? Why frame in terms of misunderstandings? What might you want people to believe and feel about the issues and people involved?

The remainder of the meeting included talks from four BRAIN neuroethics-funded researchers:

Incorporating concerns of users and investigators in neurotechnology development

[Winston Chiong](#), PhD (University of California, San Francisco) shared results from his neuroethics research from two perspectives:

- Investigators' ethical concerns
- User/patient experiences

Dr. Chiong discussed these perspectives in the context of ongoing experiments involving intracranial electrophysiology. For instance, what are the ethical concerns regarding recruiting patients undergoing neurosurgery to participate in a human research study? Specifically, the research focused on two types of studies: 1. Opportunistic, which carries marginal risk to participating but no direct benefit to the patient participant; and 2. Experimental, which carries higher risk but also potential benefit to the patient participant. Based on interviews with investigators, patients, and caregivers, Dr. Chiong's research revealed a need for neuroethical guidance around issues such as increased pressure on patients to participate in certain types of studies. In addition, there were concerns raised about how to properly obtain informed consent and who should obtain that consent. For example, the neurosurgeon may be knowledgeable on surgical risks but create a perception of coercion for the patient participant, whereas a study coordinator may be perceived as a neutral party but may also know less about the study's surgical risks.

Personality Change in the Context of Parkinson's disease and Deep Brain Stimulation

[Cynthia Kubu](#), PhD (Cleveland Clinic) presented research looking at deep brain stimulation (DBS)-treated Parkinson's disease patients' perceptions of control (e.g., control of symptoms, person, device, and overall control). Her team also interviewed patients to gain an understanding of their motivations for choosing to have DBS surgery. Their preliminary findings indicate that existing outcome measures do not fully capture patients' goals and motivations and that commonly cited goals for treatment often include symptoms that are not well treated by DBS. In addition, the patients' top treatment goals change over time. Together, these findings suggest the need for more in-depth communications with patients throughout the course of treatment, including during the consent period.

Neuropsychiatric and Movement Disorders

[Gabriel Lazaro-Munoz](#), JD, PhD, MBE (Baylor College of Medicine) presented preliminary research on the neuroethics of adaptive DBS (aDBS), which records brain activity and stimulates brain regions only when specific signals are detected. In particular, his presentation focused on the perspectives and experiences of patient-participants, caregivers, and those who declined to participate in studies. In general, patients who participated in aDBS studies were not concerned that the system would measure some of their brain activity, nor that the activity would be used to change the output of the device. Further, patients were not concerned that the devices would be storing brain activity information. In fact, patients felt positively about participating in studies that could potentially benefit others with the same condition. Interestingly, those who declined to participate in an aDBS study also expressed similar opinions as the participants. They often declined to participate based on factors that included the novelty of the device and the procedures involved.

Neuroethics of predictive MRI testing for autism spectrum disorder

[Kate MacDuffie](#), PhD, a postdoctoral researcher at the University of Washington Autism Center, presented work in progress from a [BRAIN Initiative Fellows: Ruth L. Kirschstein National Research Service Award \(NRSA\) Individual Postdoctoral Fellowship \(F32\)](#)-funded project. Working with the Infant Brain Imaging Study (IBIS), which aims to study brain development to improve early detection of autism, Dr. MacDuffie is exploring the ethical issues of whether parents of tested infants should be informed of the results, should they indicate a potential diagnosis of autism. Currently, international guidelines are inconclusive or ambiguous regarding testing for childhood-onset disorders with no proven intervention. Recently, there has been a shift towards parental discretion in terms of disclosure. Dr. MacDuffie's project aims to investigate parental attitudes towards predictive testing in IBIS, generating new knowledge to guide ethical judgments about the disclosure of predictive diagnoses in future neuroimaging research.

The next NEWG meeting will be held on January 30th, 2020.