

**Brain Research through Advancing Innovative Neurotechnologies® (BRAIN)  
Neuroethics Working Group (NEWG) Meeting  
August 20<sup>th</sup>, 2020**

On August 20<sup>th</sup>, 2020 the National Institutes of Health (NIH) Brain Research through Advancing Innovative Neurotechnologies® (BRAIN) Initiative held a virtual meeting of the [Neuroethics Working Group \(NEWG\)](#). Meeting participants discussed how neuroethics can help improve racial inequities in neuroscience research and ethics-related COVID-19 impacts on human subjects research.

[In opening remarks](#), John Ngai, PhD, Director of the NIH BRAIN Initiative emphasized the importance of recognizing and addressing racial disparities in the NIH workforce, NIH grantees, and in research. Dr. Ngai noted that by actively addressing these issues and enhancing diversity, BRAIN can benefit both the scientific community and those affected by brain diseases, including underrepresented and underserved populations. He also mentioned ongoing efforts to democratize technologies for the wider neuroscience community.

The meeting proceeded with two presentations on how neuroethics can contribute to improving racial inequities within the NIH BRAIN Initiative. First, [Kafui Dzirasa](#), MD, PhD, from Duke University, [highlighted the importance of ancestry in neuroscience and in biomedical research more broadly](#). To provide an example in modern neuroscience, Dr. Dzirasa explained that even if emerging genetic-based tools such as viral vectors show great potential in one model organism, they may not translate to other animal strains or species. Similarly, Dr. Dzirasa noted that results from diagnostic and therapeutic research with participants of European ancestry may not be transferrable to other populations, such as those of African ancestry. Thus, considering ancestry in brain research is essential to generalizing new technologies and developing effective disease therapies and personalized medicine.

Next, [Francis Shen](#), JD, PhD, from the University of Minnesota, noted that [current neuroethics and neuroscience research often ignores studying racial inequities](#). His group recently reviewed BRAIN-funded neuroimaging studies and concluded that these studies rarely report the SES or race of participants. This provides little opportunity to study and address racial inequities. To address this problem, he proposed four solutions: (1) change in reporting practice to include race; (2) change in policy to make the inclusion of race the norm; (3) change in research culture by increasing underserved community engagement; and (4) change in the research community by fostering a racially diverse leadership.

Henry T. Greely, JD, Director for Law and Biosciences at Stanford University and NEWG co-chair moderated a discussion on ways in which BRAIN and neuroethics can address racial inequities. Meeting participants suggested increasing the inclusion of diverse individuals in human research. The NEWG also proposed including more experts in racial disparities (*e.g.*, social scientists) in future neuroethics-focused meetings and discussions about diversity. In addition, they considered fostering research partnerships between these experts, neuroethicists, and neuroscientists, as well as between resource-rich and resource-limited institutions. The NEWG discussed resource allocation or facilitating the distribution of scientific resources across institutions and organizations. Lastly, they mentioned the need to develop a strategy for thoughtfully communicating about race with the research community and the public.

Next, Irene Cheng, PhD, Health Scientist in the NIH Office of Science Policy, overviewed recent activities of the [National Academies of Science and Medicine \(NASEM\) Committee on Ethical, Legal, and Regulatory Issues Associated with Neural Chimeras and Organoids](#). Dr. Cheng described four topics discussed by the committee to date, which included the state of science, welfare and ethical considerations, improving

science communication about complex topics, and definitions of consciousness, pain, “enhanced” awareness, and challenges for addressing these states. She noted that the NASEM report on ELSI findings associated with neural chimera and organoid research is scheduled to be published in March 2021.

Nina Hsu, PhD, Health Science Policy Analyst at the National Institute of Neurological Disorders and Stroke (NINDS), summarized a recent neuroethics session on research challenges during COVID-19 that took place at the [virtual BRAIN Initiative Investigators Meeting](#), which was held on June 1-2<sup>nd</sup>, 2020. Dr. Hsu highlighted main topics that emerged from the neuroethics breakout session, which included discussions about the consequences of pausing research and clinical studies, research participant vulnerability, and risk/benefit trade-offs surrounding protocol updates in response to the pandemic.

The NEWG meeting proceeded with a panel discussion on first-hand BRAIN investigator perspectives on ethical challenges in human subjects research prompted by COVID-19.

- [Maria Franceschini](#), PhD, from Harvard University, develops and optimizes non-invasive neural recording devices. Dr. Franceschini shared her experiences adapting to COVID-induced research guidelines and interacting with her institution’s Institutional Review Board (IRB). She mentioned challenges in updating research protocols to include COVID-related risks in consent forms.
- [Leigh Hochberg](#), MD, PhD, from Massachusetts General Hospital and Brown University, develops brain-computer interface devices, known as [BrainGate](#), in people with paralysis. Many of his participants live alone and/ or have limited socialization, and his study team visits them at their homes. Dr. Hochberg explained that these participants normally benefit from regular interaction with research staff, but the pandemic has greatly reduced home visits. Thus, COVID-19 has raised new unforeseen risks related to social isolation and mental health.
- [Sameer Sheth](#), MD, PhD, from the Baylor College of Medicine, uses deep brain stimulation to study and treat depression and epilepsy. These studies often require lengthy hospital stays of 7-14 days. Dr. Sheth mentioned that, due to risks associated with COVID-19 and social isolation given limited visitors policies, participant retention rates have decreased. He also mentioned challenges for research staff associated with COVID-19 testing and balancing risks with obligations to keep studies afloat.

Christine Grady, PhD, Chief of the NIH Department of Bioethics and NEWG co-chair, summarized main COVID-induced ethical issues that arose from this discussion, including the evolution of ethical concerns since the beginning of the pandemic, balancing different risks and benefits for participants and researchers, communicating with participants and researchers about COVID-19, and considering obligations to participants. The NEWG discussed providing researchers with resources for interacting with institutional IRBs and the need for guidance on how to evaluate risk-benefit ratios during COVID-19.

The meeting concluded with a closed session of the NEWG and federal staff. The next NEWG meeting will be held on Tuesday, January 26<sup>th</sup>, 2021 and a [videocast](#) will be available for live viewing and later archived.