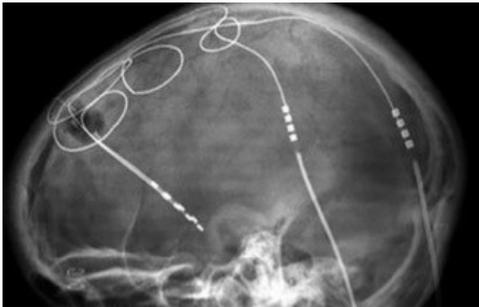


Neuroscience advances have brought important ethical questions to light.

The NINDS Neuroethics Program mission is to work with the NINDS, NIH, and NIH stakeholders to identify and navigate ethical challenges and implications of neuroscience research programs and discoveries, and to facilitate neuroscience progress.



NINDS-funded researchers recently developed a closed-loop, adaptive deep brain stimulation (DBS) system for Parkinson's disease that uses real-time neural data to fine-tune stimulation.¹

NEUROETHICS RESEARCH HIGHLIGHTS

Cynthia Kubu, Ph.D., at the Cleveland Clinic teamed up with an ethicist and a neurosurgeon to study the nature and extent of personality changes following DBS for the treatment of Parkinson's disease. Their work will facilitate enhanced informed consent and may allow clinicians to ease to fears of patients with DBS.

Ruth Ottman, Ph.D., at Columbia University is studying the psychosocial impacts of genetic information on people with epilepsy, which is associated with stigma, discrimination, and a reduced quality of life. Her findings will inform education programs on the role of genetics in epilepsy and genomic medicine.

NINDS NEUROETHICS



WHAT IS NEUROETHICS?

Neuroethics is a field that studies the ethical, legal, and societal implications of neuroscience.

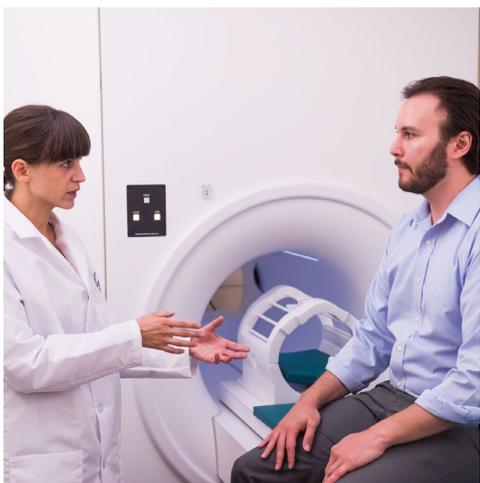
Advances in our understanding of the brain and ability to monitor and modulate brain function can raise unresolved ethical questions, such as those related to privacy, personal identity, justice, and autonomy. Such questions may include:

- Do neural data raise unique privacy concerns? What differences exist in vulnerability of different patient or participant groups to potential risks associated with neural data sharing?
- What are the implications of identifying biomarkers of pre-symptomatic disorders?
- What are the ethical issues raised by computational phenotyping of individuals based on brain data?
- Who benefits from advances in neuroscience?
- What are the ethical challenges posed by first-in-human trials with new therapies for neurological disorders? How are the risks and potential benefits balanced?

Neuroethicists can work with neuroscientists to identify and address ethical questions that arise in neuroscience research. As such, neuroethics can empower neuroscience research and help inform how studies are designed, conducted, interpreted, and applied. NINDS participates in several trans-NIH programs that support partnerships between neuroethicists and neuroscientists.

How is neuroethics research conducted?

Utilizing a series of analytical and philosophical frameworks² to identify and explore the underlying values and assumptions of a variety of stakeholders, a neuroethicist can work as part of a research team to help inform how neuroscience research is designed, conducted, interpreted, and applied. **Neuroethicists work to anticipate and help mitigate challenging value conflicts – particularly those that may arise given the privileged status the brain has in human life and self-identity – to empower neuroscience research and clinical practice.**



NEUROETHICS FOR THE NIH BRAIN INITIATIVE

The NIH Brain Research through Advancing Innovative Neurotechnologies® (BRAIN) Initiative (<https://braininitiative.nih.gov/>) aims



to develop innovative tools and neurotechnologies to advance our understanding of the human brain. The Initiative's neuroethics efforts include:

- Funding neuroethics research projects within the scope of the BRAIN Initiative
- Managing the Neuroethics Working Group (NEWG) and organizing topical workshops e.g., *Ethical Issues in Research with Invasive & Non-Invasive Neural Devices in Humans*
- Facilitating collaborations between BRAIN-funded neuroscientists and neuroethicists
- Identifying relevant ethical questions within the NIH BRAIN Initiative research portfolio

NIH is leading the way for proactively considering and addressing potential ethical considerations as the BRAIN Initiative leads to novel ways of measuring and influencing the activity of the brain. Having discussions in real time is of paramount importance as clinical researchers investigate the use of such tools to reduce the burden of brain disease.

– Walter Koroshetz, M.D., NINDS Director

HAVE AN ETHICS-RELATED QUESTION?

The NIH Clinical Center Department of Bioethics offers a bioethics consultation service (www.bioethics.nih.gov/clinical/consultation.shtml) for anyone who works at the NIH or participates in research at the NIH Clinical Center. The NINDS neuroethics program offers consultation on neuroethics questions for NINDS employees. Please contact:

Khara Ramos, Ph.D., Director
khara.ramos@nih.gov or

Saskia Hendriks, M.D., Ph.D.,
Consultant
saskia.hendriks@nih.gov

To learn more about the NINDS neuroethics program, funding opportunities, and other resources please visit:

www.ninds.nih.gov/Current-Research/Focus-Tools-Topics/Neuroethics

And see: *Neuroethics Guiding Principles for the NIH BRAIN Initiative*, Greely et al., J Neurosci. 2018; *Ethical Challenges of Risk, Informed Consent, and Posttrial Responsibilities in Human Research With Neural Devices* by Hendriks et al. JAMA Neurology, 2019; and *Neuroethics: Fostering Collaborations to Enable Neuroscientific Discovery*, Farahany & Ramos, American Journal of Bioethics Neuroscience, 2020.

¹ Swann NC, de Hemptinne C, Thompson MC, Miocinovic S, Miller AM, Gilron R, Ostrem JL, Chizeck HJ, Starr PA. *Adaptive deep brain stimulation for Parkinson's disease using motor cortex sensing*. J Neural Eng. 2018 Aug;15(4):046006.

² Farah MJ. *An ethics toolbox for neurotechnology*. Neuron. 2015 Apr 8;86(1):34-7.