Researchers highlight benefits of sharing human brain data

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In recent years, the scientific community has seen a push for more

findable, accessible, interoperable, and reusable (FAIR) neurophysiology data sharing. While certain measures have been put in place by institutions such as the National Institute of Health (NIH) to promote more FAIR data sharing, some researchers remain hesitant and unwilling to share their data beyond minimum requirements due to multiple disincentives.

In a new *Neuron* article, a team of researchers, led by co-authors Dr. Vasiliki Rahimzadeh, assistant professor at the Center for Medical Ethics and Health Policy at Baylor College of Medicine, and Dr. Kathryn Maxson Jones, assistant professor of history of technology at Purdue University and formerly a Senior Research Assistant in the Center for Medical Ethics and Health Policy at Baylor during the time of the study, profile three successful instances of data sharing from the NIH BRAIN Initiative Research Opportunities in Humans (ROH) Consortium to highlight the benefits of FAIR data sharing.

"This group is focused on how to maximize the scientific utility of human neuronal data through broad and secure data sharing," explains Rahimzadeh. "While there has been a lot of attention paid to scientific benefits of data sharing, such as researchers being able to learn from others and expand their own work, far less has been paid to the professional and other social benefits. These value propositions are important for incentivizing researchers to share data more often beyond what is required as a condition of their funding."

The paper showcases examples of successful data sharing from research groups at the University of Pennsylvania, Cedars-Sinai Medical Center, and Harvard Medical School and Massachusetts General Hospital involving intracranial electrophysiology data from patients. When shared, the data in question was de-identified to protect patient privacy, reformatted into standardized file types and uploaded to institutional or NIH archival databases, where it has been and is being reused for new

research, education, training and tool development opportunities.

Rahimzadeh said that by sharing data, the research groups discussed in the paper were able to not only open new doors for collaboration with other groups, but to also support replicability studies that overall enhance scientific rigor.

"The benefits to users include expanding both the diversity and volume of datasets available for research and being able to combine multiple datasets together to find new associations or conduct subgroup analyses that previously might have been infeasible," she said. "For producers of data, there are benefits of supporting new scientific collaborations and contributing to professional development of trainees who will continue a culture of data sharing."

Rahimzadeh added that by sharing their data, investigators increase the visibility of their labs, reduce redundancies in similar research studies and benefit from others identifying errors in code or analysis that might otherwise have remained undetected.

"Many pressing research questions about the brain and nervous systems today require analyses of data that are more voluminous and multi-faceted than any single laboratory can reasonably be expected to produce. This makes sharing data all the more important. Additionally, sharing data has had tangible benefits in other fields of life science, such as genomics," said Dr. Maxson Jones, the co-lead author on the paper, who is now at Purdue University. "Our paper shows that investing in the labor of sharing data in standardized formats comes with its own payoffs."

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