

The National Institutes of Health Neurobiobank: A Federated National Network of Human Brain and Tissue Repositories

To the Editor:

The National Institutes of Health (NIH) Neurobiobank Workgroup, representing the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute of Mental Health, and the National Institute of Neurological Disorders and Stroke (NINDS), was created to evaluate brain and tissue repositories they support. It was found that a more coordinated approach could improve efficiency, tissue quality, and availability and that a public outreach campaign was needed to increase awareness about brain donation for research. A federated model is being implemented, using a single web-based system to integrate a national network of brain banks, the NIH Neurobiobank (1).

The NIH Neurobiobank Workgroup has completed a thorough analysis with input from constituents (researchers, disease advocates, and brain banking experts) including a 1-day workshop (2) at NIH in May 2012. Based on all of the information analyzed during this process, a comprehensive new approach to brain and tissue banking has been developed with the goals of increasing availability of tissues, simplifying access to biospecimens, providing more uniform clinical/phenotype data, and improving efficiencies in existing resources and infrastructure. The NIH Neurobiobank will emphasize standardized practices and quality management, while retaining principal investigators as the focus of donor recruitment. Beginning in 2013, support for brain and tissue repositories will shift from grants to contracts, allowing greater oversight and coordination. This approach is scalable and could be expanded to partner with other organizations.

With the ever increasing scale of “omics” studies, it is often necessary to obtain specimens from multiple repositories, each with potentially different access policies, methods of collection, and varying quality metrics, making it difficult to run a well-controlled experiment. In addition, the disease- and disorder-specific focus of existing brain banks has limited the collection of tissues because they exclude donors who have disorders outside their primary area of research. This is a tremendous missed opportunity. Investigators with particular disease expertise provide the best opportunity to recruit subjects from the community and accurately phenotype patients. The NIH Neurobiobank will encourage investigators to use and expand their networks to donors with a broader array of diseases and disorders along with essential clinical and phenotypic data. The incentive to collect a broader population of donors is increased availability of specimens from all repository sites.

To be fully successful, NIH will need to partner with medical examiners and organ and tissue procurement organizations to help in identifying potential donors. Equally important are patient and disease advocacy groups to educate the public about the need for tissue donation. It is important to increase the number of preregistered donors across disease categories, including healthy donors. Successfully increasing the number of prospective donors will require reducing stigma and establishing a culture of donation.

While brain and tissue repositories obtaining high-quality tissue may not need to change their practices, there is value to end users of standardized practices. Assessing the quality of

sample tissue across multiple sites is one way to identify variability and identify opportunities for improvement. Additionally, the use of common data elements (e.g., NINDS common data elements: <http://www.commondataelements.ninds.nih.gov/>) to report clinical and biological data will greatly increase the value of these specimens and associated data.

Success will be assessed on metrics of tissue quality (e.g., quality and quantity of nucleic acids and proteins for each tissue type), tissue access and distribution, and publications and advances resulting from these resources.

An external Ethics and Science Panel (ESP) of three to four experts in neuropathology; biospecimen banking; and the ethical, legal, and social issues of human tissue research will be established to provide expert perspective and ensure transparency. The ESP will provide a semiannual review of repository functions and review of its activities including tissue distribution.

Broad sharing of tissues is expected and policies have been developed to address access to rare or limited tissues or unusual requests. Requests will be transparent to the principal investigators of each brain and tissue repository, the ESP, and to NIH staff.

Private legacy collections will be accepted into the Neurobiobank on a case-by-case basis following review by the appropriate experts and approval by the NICHD, NIMH, and NINDS directors. Criteria to be considered will include tissue quality, nature of consent, completeness of clinical and phenotypic data, and cost of repatriation.

In summary, the goals of the NIH Neurobiobank are to increase availability of human brain tissue by increasing donor recruitment through increased outreach, expanding the number of brain and tissue repositories, simplifying access to biospecimens, and standardizing documentation of tissue quality. The NIH Neurobiobank will achieve greater efficiency by increasing coordination and collaboration and capitalizing on the skills and resources of brain-banking experts who have a history of successfully working in their communities and operating high-quality brain and tissue banks. It is critical that we increase the availability of human brain tissue for research in this time of unprecedented scientific opportunity to identify the mechanisms underlying human brain diseases and disorders.

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1. National Institutes of Health (2010): Grants & Funding. Funding opportunities and notices. Request for Information (RFI): Acquisition, Processing, Storage, and Distribution of Human Brain Tissues to Advance Understanding and Treatment of Addiction; Neurological, Psychiatric, Developmental, and Mental Disorders; Neurological Diseases; Normal Brain Development; and Aging. Notice Number NOT-MH-10-034. Available at:

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