NEUROSCIENCE & PUBLIC POLICY SEMINAR

LARGE DATASETS AND DATA RELEASE POLICIES: PROMOTING UTILITY WHILE PROTECTING RESEARCH PARTICIPANTS

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Genome researchers have led the scientific community in developing policies and infrastructures for sharing large datasets, even enforcing prepublishation data release for some large "resource generating" projects. Several other research communities have developed similar policies. The NIH now has formal guidelines and a technological infrastructure for the sharing of data from genome-wide association studies. Regulatory and ethical norms have permitted and even promoted data sharing when the data could be anonymized. Until recently, researchers and oversight bodies have treated genomic data as though they could be anonymized by stripping off extrinsic identifiers. However, technological advances in genotyping, sequencing and data mining, along with the increasing use of genotyping and sequencing in a variety of non-research contexts, have rendered genomic information capable of being used to identify individuals in data sets. If we cannot use anonymity as the tool for protecting research participants from informational harms, then what protections can we develop that will still allow data to be widely available to a variety of scientists? This presentation will describe the problem and then describe several mechanisms that could be used, probably in combination, to achieve the dual goals of subject protection and wide availability of large datasets.

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