DATA SHARING IV: ETHICS OF DATA SHARING

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ETHICAL PERSPECTIVES ON DATA SHARING

In addition to generating technological and practical prescriptive guidelines, the new thrust for data sharing properly stimulates examination of ethical behavior for both suppliers and users of research data. While continuing to encourage neuroscience data sharing, we provide perspectives on how the culture of research might adapt to these new capabilities. Our goal is to stimulate informed collegial discussion both of ethical guidelines for data sharing and also of potential mechanisms for examination, evaluation, and resolution of conflicts between the right to know and other concerns including intellectual property and privacy. Adoption of such guidelines by experimental and clinical neuroscience communities will increase access to information and foster scientific progress.

TOWARDS COMMUNITY DEVELOPMENT OF ETHICAL GUIDELINES

Finally, we call for broad input to developing ethical guidelines, including data sharing practices, both for the neuroscience research community, including producers, sharers, and users of data. Most important, we call for collegial and transparent mechanisms for the resolution of conflicts, structured to balance the interests of producers and sharers of data, users of shared data, the neuroscience research community, and society overall.

URL:
- Evolving versions of these and other perspectives may be found at: datasharing.net

BALANCING PRIVACY AND SHARING

While respecting the strictures imposed by HIPAA and the Common Rule, we suggest that refusal to share human subject data, when such data is ethically justifiable, contradicts the open access model that sharing should promote. In such cases, the burden is on the party declining the data-sharing agreement—shared subject data should be weighed against the mandate to protect human subjects and maintain confidentiality.

ELEMENTS OF ETHICAL DATA SHARING

- Acceptance of the responsibilities of data sharing
- Accessibility of data without unreasonable delays or restrictions
- Assurance of academic freedom to share data and to utilize shared data
- Maintenance of the integrity of data to be shared
- Responsible stewardship of shared data
- Recognition of the integrity of acquired data
- Assumption of individual responsibility for shared or shared data, and recognition of individual obligations
- Development and adoption of guidelines incorporating individual, group, and societal responsibilities
- Each of these in the service of
- Maximizing the scientific knowledge extractable from available data

ACKNOWLEDGMENTS:

We also ask that re-use of any data from this site include as well an acknowledgment such as: ‘Data used in this study were delivered via neurodatabase.org—a neuroinformatics resource funded by the Human Brain Project.’