



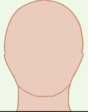
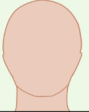




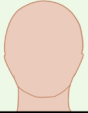
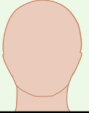







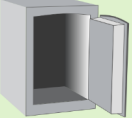

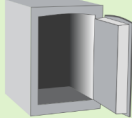

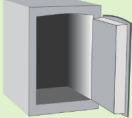

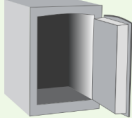
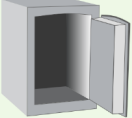


| | Raw | Pseudonymous | | | Anonymous | |
|-------------------------------|---|---|---|---|--|--|
| | Personal | Key coded | Pseudonymous | De-identified | Anonymous | Aggregated anonymous |
| Direct identifiers | Intact  | Eliminated or transformed  | Eliminated or transformed  | Eliminated or transformed  | Eliminated or transformed  | Eliminated or transformed  |
| Indirect identifiers | Intact  | Intact or partially intact  | Intact or partially intact  | Partially intact  | Eliminated or transformed  | Eliminated or transformed  |
| Re-identification | High probability  | Medium probability  | Medium probability  | Low probability  | Not Possible  | Not Possible  |
| Safeguards for sharing | Required  | Varies under different regulations   | Varies under different regulations   | Varies under different regulations   | Not required  | Not required  |

Supplementary Figure 1. How laws perceive pseudonymous, de-identified, and anonymized neuroimages with high-spatial resolution and the different levels of risks associated with sharing. Figure / Table showing core concepts used to describe identifiability of data originating from human subjects. Terminologies differ under different regulations, e.g., the term 'de-identified' is used in HIPAA while 'pseudonymisation' is used in the GDPR. These and other regulations in different parts of the world have different requirements for safeguard and control of these types of data. Only anonymized data can be shared openly according to GDPR, whereas other regulations require varying degrees of safeguards, often few or none, for some of the other categories. It must also be noted that following advancements in machine learning and artificial intelligence, the possibility of achieving anonymity in datasets has become debatable.

The International Brain Initiative: partner projects and data governance status

Although united in their desire to revolutionize the understanding of the brain globally through open data and sharing, each of the large brain projects that comprise [the membership of the IBI](#) has its own unique character and organizational structure as regards data. They are also at different levels of maturity, with some still in the planning phases. The diversity of these initiatives impacts any discussion of data governance such as the mechanisms through which data governance is developed and delivered, are different depending on the project. Individual researchers in these projects must comply with an array of data sharing policies and regulations within their home countries/regions that are largely established by their individual institutions and the funding agencies

supporting the projects. Thus, while some of the projects are informed by clear structures, others are distributed without a clear international data governance pipeline.

| IBI Member | Funder policies | Project policies | DS | UR | Ex | L | DUA | IP | PP | IDG | T | IR | SC | HD | AD |
|-----------------------------------|--|--|----|----|----|---|-----|----|----|-----|---|----|----|----|----|
| Canada Brain | | *CONP Ethics & Governance •CONP Publication and Commercialization | X | X | X | X | | X | X | | | | | X | |
| European HBP | H2020 Regulation H2020 Guidelines on Open access | HBP Data Policy Manual | X | x | | X | X | X | X | X | X | X | X | X | X |
| Japan Brain/MINDS Beyond & SRPBS | Japan Agency of Medical Research and Development data sharing policy | | X | X | X | | X | X | X | X | X | X | | X | X |
| US-BRAIN Initiative (USBI) | Data sharing policy for the BRAIN initiative | | X | | X | | | | | | X | X | X | X | |
| US National Institutes of Health | •NIH Data sharing policy •The National Institute of Mental Health Data Archive (NDA) | | X | | X | | | | | | X | X | X | X | |
| USBI: National Science Foundation | •Dissemination and sharing of research results •Biological Sciences Guidance on Data Management Plans | | X | X | X | | | X | | | | X | | | |
| USBI: Simons Foundation | Renewable reagents and data sharing policies | | X | X | | | | | | | X | | | | |

Supplementary Table 1: Data governance policies for IBI members. This table shows the gaps that demonstrate the need for clarifying IDG that can allow global sharing.

DS = Data sharing required, **UR** = use restrictions, **EX** = exceptions to data sharing, **L** = license information, **DUA** = data use agreement information, **IP** = intellectual property, **PP** = privacy protection, **IDG** = international data governance, **T** = timeline for sharing, **IR** = infrastructure restrictions, **SC** = standards compliance, **HD** = human data, **AD** = animal data, **E** = enforcement

Comparing the needs for data governance between human and animal data

| Issue | Human data | Animal data |
|--|------------|-------------|
| Informed consent | x | |
| Sampling bias (e.g., limited inclusion criteria and underrepresentation of the diversity of the population: sex, gender, ethnicity, age etc) | x | x |
| Regulatory and ethical differences (leading to possible ethics dumping) | x | x |
| Legal basis for processing the data | x | |
| Anonymization and de-identification or pseudonymisation | x | |
| Standardization (e.g., adoption of community standards for data and metadata) | x | x |
| Data transfer agreements | x | x |
| Security | x | x |
| Retention policy | x | x |
| Data controllership and liabilities for data breach (e.g., who is liable) | x | |
| Incidental findings and reporting | x | |
| Data misuse | x | x |
| Dual use | x | x |
| Commercial exploitation | x | x |
| Access control | x | x |
| Licencing (e.g., CC licenses) | x | x |
| Intellectual property (IP) | x | x |
| Attribution (e.g., data citation) | x | x |
| Inappropriate retention | x | |
| Loss of data and unintended deletion | x | x |
| Biases and unfair discrimination towards both the participants as well as the researchers | x | |
| Benefit sharing (who should benefit from the data products if used for commercial purposes) | x | x |

Supplementary table 2: Comparing data governance needs of human and animal data. Unlike human data that is nationally or regionally regulated, there are no identifiable established legal frameworks that govern the sharing of animal data nationally or internationally. One reason for this is that the use or sharing of animal data does not raise the traditional data use concerns associated with human data such as; privacy, fairness, human rights and security. However, there are legal, ethical and practical reasons why animal data (especially NHP data) needs to be responsibly shared including; differences in animal welfare regulations, possibility of ethics dumping, IP and other licencing issues.