Brain-CODE Security and Privacy Guidelines for Data Upload

Brain-CODE is the Ontario Brain Institute's (OBI) neuroinformatics platform that supports the collection, storage, processing and analysis of multi-dimensional data for a variety of brain disorders. OBI is recognized as a "Privacy by Design" ambassador in virtue of its extensive informatics governance framework, privacy and security practices, and technologies related to data management on Brain-CODE. This designation refers to the mitigation of privacy and security risks through a proactive and preventative approach to research data management by embedding privacy and security measures into the design of its systems and practices. A number of documents related to privacy and Brain-CODE are available on the Brain-CODE website, including the Informatics Governance Policies and Security Policies as well as information included in the "Getting Started" and "Frequently Asked Questions" pages. Abiding by the policies and procedures in relation to data upload on Brain-CODE is essential to ensure the quality of the data, to enable data sharing and analysis, and, ultimately, to maximize the value of research.

The following outlines OBI's guiding principles related to the upload or transfer of research data to Brain-CODE. Please also refer to your own institutional guidelines regarding privacy and security related to data management.

Part A. Data Entry Pre-requisites

1) While OBI takes many precautions to ensure that unapproved personal health information (PHI) is not entered into Brain-CODE database, it is ultimately the responsibility of researchers to ensure that the data entered or transferred to Brain-CODE abides by the Research Ethics Board (REB) approved participant informed consent forms of their respective institution.

2) Please ensure that you only enter data that participants and REBs approve to input on Brain-CODE. Non-adherence to informed consent and institutional REB authorizations regarding PHI entry is a violation of participant privacy and may be reported as a formal security and privacy incident. OBI has developed Generic Consent Language (available on the governance page) to add to your consent forms. This language will ensure that participants are informed of their data and PHI being stored on Brain-CODE and will benefit your study.

3) It is imperative that participant personal information is not shared with unauthorized research personnel.

Part B. Capture Tools and User Accounts

1) During data capture training, training instances of tools such as REDcap, OpenClinica, SPReD, LabKey, Subject Registry, or other capture tools will be deployed. However these are not housed within the secure Brain-CODE environment and it is therefore important that users never enter study data into the training instances.

This includes any study data which may or may not contain PHI. Only test/sample data should be entered into Brain-CODE on training instances of these software tools. Study data in the context of this document includes most information acquired from the individual participants (e.g., images, scores, SNPs) but does not include metadata elements, such as subject IDs, session names or data upload dates. For a list of study data exemplary items please refer to Appendix 1.

2) Study data should not be shared via email, even if these data appear to have been de-identified.

   Email is not a secure platform and data sent via email could be intercepted and accessed by multiple individuals or systems during their transmission. Please contact help@braincode.ca if you need help transferring data to Brain-CODE securely when the data capture tools are not an option.

3) Study data should not be stored on the Brain-CODE portal's File Repository.

   The File Repository on the Brain-CODE portal is designed to store administrative documents to help with research project management. The File Repository is not designed to track or process study data for storage or sharing. This includes any study data which may or may not contain PHI. Suitable Brain-CODE user accounts will be created for data read/write access by collaborators on designated data capture tools (e.g., REDCap, OpenClinica, SPReD, etc.).

4) Users should not share their username and password with another person.

   Details of your Brain-CODE login credentials (username, password) must be kept strictly confidential. Access to Brain-CODE software requires a formal account request, validation of credentials, and training which help to ensure that only qualified persons may perform operations on the platform. If you are part of an OBI Integrated Discovery Program (IDP), please consult with your IDP Program Manager for information on how to create an account.

5) Users should not upload data on Brain-CODE while their computer/device is connected to a public network which can be classified as an unsecured network that does not require a password or network key for internet access.

   While a secure connection is established between Brain-CODE servers and your computer/device browser, connecting to public networks places your computer/device at an increased risk to security vulnerabilities.

6) Users should avoid saving login credentials on personal computers/devices by default. Users should never save login credentials on shared computers/devices. This reduces the risk of unauthorized users from accessing Brain-CODE.

7) Please log out of Brain-CODE and all associated data capture tools when you are finished your session. This reduces the risk of unauthorized users from accessing Brain-CODE.

If you have any additional questions or concerns about participant data security and privacy on Brain-CODE, please visit www.braincode.ca/content/faq or contact governance@braincode.ca.

Appendix 1: Study Data Tables

Study Data Examples *(unacceptable to email)*
Personal health information (names, date of birth, email addresses, postal codes, telephone numbers, medical records, data acquisition dates, other demographic information, etc.)
Clinical assessment scores
Imaging data
Gait data
Ocular data
Behavioural data
SNPs

Non-Study Data Examples *(acceptable to email)*
Study IDs
Study titles
Brain-CODE Subject IDs
Data upload dates
Study sites
Program names
Other metadata elements

Please contact governance@braincode.ca if you are unsure about how to input, transfer or share a specific data type.