

What is Brain-CODE

Brain-CODE is OBI's state-of-the-art neuroinformatics platform designed to store, manage and analyze data – a "shared brain" for researchers in Ontario and beyond.

Guiding Principles of Brain-CODE



Private and Secure

All research participants are protected by a strong data governance framework, removal of data identifiers, and strong firewalls.



Open and Collaborative

Researchers worldwide can access data and post requests for data available online.



Interdisciplinary and Integrated

Various types of data are collected across brain disorders for easy analysis.



Patient-Centred

Data Access Committee includes members from the community to ensure the public voice is heard.



Impactful

Data Access Request Committee review includes questions about research impact before allowing access to data.



Standardized

Allowing an apples-to-apples comparison of datasets within and between brain disorders.



[Click here to learn more about the guiding principles](#)

Where does the data come from, and where does it go?

Within the Brain-CODE platform, data is gathered and stored in a structure format consisting of three levels.

ZONE 1

Raw data collected through to OBI's research programs is stored in the database.

ZONE 2

All data is scrubbed to remove any personal identifiers and linked with external databases through a secure linking protocol.

ZONE 3

External researchers can request access to data. Upon approval, they can use the data to supplement their own findings and accelerate the rate of innovation and discovery.



[Click here to learn more about data management and zoned architecture](#)

Open Data Releases through Zone 3:

- ✓ Promote data sharing
- ✓ Accelerate scientific discovery
- ✓ Verification of results
- ✓ Efficient use and reuse of participant data

How is the data kept safe?

A robust governance structure ensures that Brain-CODE maintains a high level of quality and security that is consistent with OBI's vision and mandate.

Brain-CODE security is ensured and maintained by the Governance trifecta:



Prior to data upload into the database, OBI ensures the necessary agreements are in place with each site.



The Research Ethics Board reviews the recruitment process, consent forms, and protocol for ethical acceptability and compliance.



All consent forms are reviewed to ensure consistent Brain-CODE terminology and language is used around data sharing and linkage.

Brain-CODE Governance Committees:

Brain-CODE Advisory Committee: Advises on the direction and progress of Brain-CODE, ensuring the platform meets international best practices for data organization, sharing and analysis.

Brain-CODE Data Access Committee: Makes recommendations to the Informatics Steering Committee regarding the release of data to third parties.

Information Security Committee: Identifies, implements and maintains security and privacy standards for all data and infrastructure in Brain-CODE.

Informatics Steering Committee: OBI Executives provide oversight on issues relating to the establishment and management of Brain-CODE.

For data sharing to proceed, approval is required from:

- ✓ Research Ethics Board
- ✓ Data Access Committee
- ✓ Steering Committee



[Click here to learn more about Brain-CODE's governance policy](#)