Ontario Brain Institute – Brain-CODE

In 2010, the Government of Ontario created the Ontario Brain Institute as an independent, not-for-profit corporation. Its goal is to bring together the province’s top brain researchers and business experts who can turn their discoveries into products and services.

The Ontario Brain Institute’s Brain-CODE (Centre for Ontario Data Exploration) will store clinical data, particularly brain images, as well as gene and protein data from studies in a broad range of brain conditions. These conditions include: cerebral palsy, epilepsy, traumatic brain injury, addiction, neurodegenerative diseases, autism, and depression.

Researchers will be able to access clinical and biospecimen data from these conditions as well as information derived from research in genomics, proteomics, bioinformatics, health services and even economics. The ultimate goal of Brain-CODE is to make information easily available to researchers while adhering to strict patient privacy guidelines.

Patient privacy a crucial factor in database design

In designing Brain-CODE, the team worked with the Information and Privacy Commissioner of Ontario, Dr. Ann Cavoukian, and adhered to “Privacy by Design” principles developed by her office.

Privacy by Design (PbD) is an approach to protecting privacy by embedding it into the design specifications of technologies, business practices, and physical infrastructures. That means building in privacy up front – right into the design specifications and architecture of new systems and processes.

Commissioner Cavoukian commented that, “The OBI is engaged in highly innovative research. By incorporating the principles of Privacy by Design into their overarching program, they can advance research on a broad range of neurological disorders, while protecting the privacy of research subjects, thereby achieving a positive sum, ‘win-win’ solution.”

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