



NEUROMOD

LE PROJET COURTOIS SUR
LES MODÈLES NEURONAUX

THE COURTOIS PROJECT
ON NEURONAL MODELLING

Courtois NeuroMod Databank Management Rules and Procedures

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Abbreviations

CER VN Comité d'éthique de la recherche en vieillissement et neuroimagerie.

CCSMTL Centre intégré universitaire de santé et de services sociaux du Centre-Sud-de-l'Île-de-Montréal.

Courtois NeuroMod Courtois Projet on Neuronal modelling

CRIUGM Centre de recherche de l'Institut universitaire de gériatrie de Montréal.

MRI Magnetic Resonance Imaging

MEG Magnetoencephalography

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This document defines the rules and procedures for the management of the Courtois NeuroMod databank, including governance.

The scope of this document includes the constitution of the databank as well as data collection, storage, distribution and usage in accordance with the ethical standards and laws applicable in Quebec and Canada.

1. Description of the database

1.1 Content

The Courtois NeuroMod database contains a structured set of personal information, including:

- Basic demographic and phenotypic information, such as age, gender, hand laterality, languages spoken, video game playing habits, level of education, lifestyle habits, ethnicity, auditory and visual perception.
- Biosignals, such as skin conductance, electrocardiogram, cardiac plethysmography, respiration, eye movement.
- Structural and functional Magnetic Resonance Imaging
- Magnetoencephalography
- Behavioral data acquired during cognitive tasks, such as identifying objects in an image, and video game play (such as Mario).

These data do not contain any information that would allow participants to be easily identified. Data have been denormalized and participants' faces have been removed from the MRI images. In addition, none of the data collected is a known test for diagnosing a clinical condition. See the project's online documentation for a detailed description of available data <https://docs.cneuromod.ca>

These data have been collected as part of the Courtois NeuroMod research project, entitled "Comprehensive characterization of human brain activity in the context of natural stimuli for the development of individual brain models", established with funds from the Courtois Foundation. The implementation of this research project was initially approved on October 26, 2018, then renewed on September 19th, 2019, October 26th, 2020 and October 20th, 2021 by the CER-VN of the CCSMTL.

1.2 Objectives

The main objective of the Courtois NeuroMod database is to store the data acquired in the Courtois NeuroMod project, in accordance with the ethical and legal standards in force in Quebec and Canada.

A second objective is to share this data with the scientific community for research purposes in order to deepen our understanding of artificial and biological intelligence.

1.3 Participants

1.3.1 Inclusion criteria

- Participants in good health
- Be 18 years or older
- Consent to answer questions about their state of health and lifestyle to verify their eligibility for the study.
- Be able to commit to a study period of at least 5 years.

1.3.2 Exclusion criteria

- Have hearing impairment that prevents participants from hearing stimuli.
- Have visual impairment that prevents participants from seeing stimuli.
- Have certain neurological disorders.

1.3.3 Exclusion criteria for MRI

- Being pregnant.
- A heart pacemaker (or pacemaker).
- A defibrillator (a device for the rhythm of the heart).
- A prosthetic heart valve (a prosthetic heart),
- A Swan-Ganz catheter (a tube in the pulmonary artery on the chest).

- An insulin or metallic nutrient pump under the skin.
- A neurostimulator, a brain aneurysm clip (a clip in a blood vessel in the brain).
- A metal prosthesis or rods (following surgery).
- A cerclage (metal support on a bone).
- A cochlear or ocular implant (an implant in the ear or in the eye).
- A penile implant.
- An intraocular metallic fragment (a metallic debris in the eye).
- A patch on the skin for the administration of a drug.

Other situations that may cause the termination of the MRI exam:

- The presence of piercings, tattoos, permanent makeup.
- Dental braces.
- Acute claustrophobia (unpleasant feeling in enclosed spaces).

1.3.4 Exclusion criteria for MEG

- Electrostimulator implants (e.g. pacemaker, neurostimulator, cochlear prosthesis, insulin pump, heart valve prosthesis).
- Metallic foreign bodies (e.g. bullets, shell fragments, metallic splinters).
- Orthopedic prostheses (ex: nail, screw, plate).
- Tattoo or permanent makeup.
- Drilling.
- Magnetic or non-magnetic implant (ex: stent).
- Diaphragm, IUD.
- Dental prosthesis, orthodontic appliance (fasteners or discrete wires).
- Ocular implant or prosthesis.
- Transdermal system (e.g. metallic coated dermal patch, patch).
- Dental braces (in some cases only).

2. Management and administration

2.1 Databank ownership and administrator

The designated Principal Investigator of the Courtois NeuroMod project, Professor Pierre Bellec, is the instigator of the Courtois NeuroMod database. He acts as an administrator of the database, see section 2.2..

Which means he is responsible for the conservation, storage and security of the data collected. He is also responsible for distributing data to users of the Courtois NeuroMod databank.

At all times, participants of the Courtois NeuroMod project own their data. Under no circumstances will the data stored in the databank be sold and it will only be used for scientific research purposes.

2.2 Fiduciary and administrator

The Courtois NeuroMod databank is non-profit and is under the trust of the CCSMTL. The latter is imputable and responsible for the database.

The responsibilities of the administrator include the following:

- Establish the operating rules of the databank in accordance with applicable standards.
- Appoint the members of the management committee, who administer the data bank and ensure that the members of the management committee receive adequate training to manage the databank.
- Designate the members of the access committee, that are responsible for authorizing user access to the bank.
- Ensure that the rules and procedures set out in this document are respected by the management committee, the user access committee and the users of the bank.

2.3 Management committee

Management of the Courtois NeuroMod database is the responsibility of the administrator, who entrusts members of the management committee with the responsibilities listed below. The management committee acts as an

interface between users and the data bank. The management committee is responsible for:

- Receive access requests.
- Ensure that access or renewal requests are assessed according to the management framework by the access committee (see Section 2.4).
- Inform users of decisions relating to their requests.
- Ensure the transfer of data if the project is approved.
- Guide users on access procedures.
- Ensure that the confidentiality of information concerning bank data is respected.
- Ensure compliance by the users of the bank with the rules set out in this document as well as the data transfer agreement, in particular that the use made of the data is in accordance with the project registered by users and that the users do not distribute the data outside of the bank.
- Monitor data usage.

2.4 User access committee

The access committee reports to the data bank administrator and the management committee and it is responsible for for the evaluation and renewal of access request to the data of the bank, in particular:

- Evaluates applications for access by potential users. See section 3.2 for a description of eligibility requirements and the evaluation procedures of access requests.
- Establishes whether there have been breaches of the bank's access rules.
- If necessary, revoke the access rights of a defaulting user without the possibility for the latter to contest this decision.

The user access committee is chaired by the administrator of the Courtois NeuroMod databank. Any decision of the access committee is taken by majority vote, with a quorum of 3 members. In the event of a tie, the final decision is given to the committee chair.

This committee is made up of members of the Courtois NeuroMod project research team, all affiliated with CRIUGM.

The members of the access committee continue to fulfill their role as long as they are available, willing and active in the project. The databank administrator invites new members to join the committee when a place becomes vacant.

Members of the committee with a conflict of interest (as defined by article 3 of regulation 10.23 of the Université de Montréal) will have to withdraw from the deliberation and voting process and new ad hoc members will be invited in the case where the quorum cannot be met.

The user access committee, with the support of the members of the bank's management committee, keeps and maintains a written record of the committee's decisions, and the list of principal researchers with access to the data bank.

2.5 Financing

The Courtois NeuroMod databank is not a commercial entity. In particular, the database does not require access fees. Research funds from the Courtois NeuroMod project have enabled the creation, development and operation of the Courtois NeuroMod database.

2.6 Change of purpose, merger or transfer of the bank

The data bank will be kept for as long as it can be useful for the advancement of scientific knowledge.

Any procedure aimed at changing the purpose of the Courtois NeuroMod database and any procedure related to the merger or its transfer must be the subject of consultation and agreement with the administrator of the data bank and the CCSMTL, as well as an evaluation by the CER VN. In addition, the procedures for making this change should comply with the requirements established by the CCSMTL.

In the event that the administrator is unable to participate in this consultation, for example for medical reasons, the scientific director of the CRIUGM will be responsible for this process.

A written notice or an e-mail, concerning the said change of purpose, the merger or the transfer of the bank must be communicated to the participants whose data are kept in the bank as well as in order to inform them of the changes regarding whom to contact (i.e resource persons, managers, etc.).

A notice in writing or by e-mail must also be sent to all users of the bank to inform them of the changes relating to their access, and the future operations of the databank.

3. Data collection

3.1 Provenance of the data and recruitment strategy

When an individual consents to participate in the Courtois NeuroMod project, this individual consents that all personal data collected during their participation in the project, as well as all responses to surveys, tests and examinations will be included in the databank, and made accessible to all users of the Courtois NeuroMod databank.

In addition, if an individual agrees to be re-contacted by the principal investigator of the Courtois NeuroMod project or a member of his team, this individual agrees to share their coordinates with the rest of the research team, in a way that respects data privacy.

3.2 Data access

3.2.1 Eligibility

The Courtois NeuroMod data can only be used for scientific research purposes. The research team may include commercial partners, but the principal investigator of the research team must have a position in an established research institution. This person as well as a representative of the institution both sign the data transfer agreement. The access is authorized for the principal investigator of the team, who is responsible for appropriate usage, security and sharing of data with the rest of the research team.

3.2.2 Procedure to request access

Researchers wishing to access data from the Courtois NeuroMod database must submit a request on the neuromod.ca website by following the following steps:

1. First read please read both the "Courtois NeuroMod Databank - Management Policies" as well as the "Courtois NeuroMod data sharing agreement" documents.
2. Complete the form "Access request for the Courtois NeuroMod database". This form must include a short description and summary of the scientific research project and a description of the research team. The research team will also have to file scientific approval and ethical approval with their home institution.
3. Once the access request form has been completed, the user access committee evaluates the access request and approves, if appropriate, the use of the database.
4. Once the project is approved by the user access committee, the researcher must sign the "Courtois NeuroMod Data Sharing Agreement" document. This agreement must be signed by the principal researcher of the study as well as by a person representing their institution. If non-university institutions, in particular private companies, are partners in the project, a separate agreement will be established with the partner institutions.
5. Upon receipt of the documents, an email will be sent to the user's institutional email, which they used to apply for access, that will provide them with a unique username and password. The username and password allow the research team to access and download data from the Courtois NeuroMod databank.
6. The access login information expires every year, and must be renewed using the "Renewal of access to the Courtois NeuroMod bank" form. If the research team wishes to carry out a new project whose objectives deviate from its initial request, a new access request must be submitted.

3.2.3 Project evaluation

The members of the user access committee assess whether the proposed research project is consistent with the general objectives of the initial Courtois NeuroMod project ethics application.

The access committee will not carry out a scientific evaluation of the proposed project, or assess the capacity of the research team to implement this project. The description of the research project does not need to list the details of the methods used, but must make it possible to judge the adequacy between the objectives of the proposed project and the objectives of the Courtois NeuroMod project, for which the research participants have consented to.

In the event that the proposed project seems to deviate from the original scientific objectives of the Courtois NeuroMod project, the user access committee may either firmly reject the access request, or request that the team provide more detailed information.

3.3 Open data sharing platforms

3.3.1 Github

The different versions of Courtois NeuroMod data are controlled by a technological solution called Datalad. This technology only makes the metadata public, meaning a description of the type of data present in the bank. Metadata does not contain any personal information that identifies participants, such as neuroimaging data. The only personal data that is public is the age and sex of the participants. These metadata are publicly accessible on the Github platform (github.com/courtois-NeuroMod/). If a researcher is interested in having access to individual datasets in the Courtois NeuroMod database, such as neuroimaging data, they will need to proceed with the steps described above in section 3.2.

3.3.2 Canadian Open Neuroscience Platform (CONP)

CONP has set up a directory of databanks that allows researchers in Canada and around the world to discover the datasets indexed by CONP, such as the Courtois NeuroMod databank, and to understand precisely what types of files and metadata a databank contains. However, CONP does not allow individuals to access the data as such. If a researcher wishes access to the data in the Courtois NeuroMod database, they must proceed with the steps described in section 3.2.

3.4 Derived, enriched and redistributed data

3.4.1. Publication of research results

The production of figures and data associated with figures for inclusion in scientific publications does not require specific authorization. This includes in particular:

- Individual parametric brain maps (e.g. connectivity or activation map).
- Individual connectomes
- Individual statistical parameters (reaction time, task performance).

3.4.2. Redistribution of derivatives data

If the research team wishes to redistribute derivatives data outside the Courtois NeuroMod bank, the team will have to make a new access request specifying what data will be shared, in what forms and under what conditions. The user access committee will decide on the sharing of data in the context of this specific request and may require approval from research participants. Derivatives data include, but is not limited to:

- Individual, structural or functional brain atlases.
- Data preprocessed with a different approach from that distributed by the Courtois NeuroMod team.
- Model of artificial neural networks trained using Courtois NeuroMod data.
- Annotation of videos used as stimuli.
- Annotation of physiological signals.

In case of doubt about the need to obtain authorization from the user access committee, we recommend users contact the committee (courtois.NeuroMod@gmail.com).

3.4.3. Sharing of enriched data from the Courtois NeuroMod database

Given that the Courtois NeuroMod bank aims to be a dynamic platform designed to be shared with the scientific community with the goal of accelerating research on the human brain and artificial intelligence, the user access committee could, if necessary, require that the research team grants a free license to the Courtois NeuroMod bank

so they can share and redistribute, via the bank, derived data generated by a project. Users of the Courtois NeuroMod bank will then have access to enriched data, combining de-identified data from the Courtois NeuroMod bank and data derived from users of the bank.

4. Protection of privacy of personal information and confidentiality

4.1 Policies and laws

The fiduciary, the administrator, the management committee of the Courtois NeuroMod bank, the user access committee and all users are required to comply with all applicable Quebec and Canadian laws, particularly with regard to the rules of protection of privacy of personal information and confidentiality of information.

4.2 Data coding

The data collected is modified in order to limit the possibility of identifying the participants, in particular by the use of authentication codes, by the deletion of the face in the anatomical MRIs and of any other personal information. In the data bank, participants are identified by an incremental identifier (sub-01 to sub-06) allowing the link to be made between the data contained on the server and the personal information.

4.3 Data security

4.3.1 Storage of data at CRIUGM

Paper documents containing personal information, results from data collection or evaluations are kept in filing cabinets and locked rooms and only members of the Courtois NeuroMod database management committee have access to these filing cabinets.

Personal information, including the name, gender, date of birth, telephone number and email address of the participant and the key to link the participants' code (sub-01 to sub-06) to their personal information is kept by the bank administrator on a computer hosted and secure at CRIUGM protected by a password. Authentication codes and passwords (different for computer files and the computer) are known only to the administrator and members of the bank's management committee. Daily access to the computer file is done on a single computer in a secure location at CRIUGM. Only the administrator and the members of the management committee of the bank have the key to this room. Restricted access to the persons named above as well as the protection of computer files and the computer makes it possible to maximize the security of access to information.

4.3.2 Data server

Data using authentication codes are hosted on a secure server at the CRIUGM. Access to the data server is controlled: bank users can obtain read-only access to a subset of the data, which needs to be renewed each year. Users login using unique IDs and complex keys. Authentication and data transit via the https protocol according to the most recent cryptography standards, including the periodic renewal of certificates.

4.3.3. Access for members of the management committee and the bank administrator

Only members of the management committee and the bank administrator can add, correct or remove content from the databank.

4.3.4. Users with access to data

Only users who have complied with all requirements (see section 3.2 for eligibility conditions) will have access to data from the Courtois NeuroMod databank for the duration determined in their authorization.

4.3.4. Duration of data storage

Research data will be stored for as long as they can be useful for the advancement of scientific knowledge. When no longer needed, the research data will be destroyed.

Note that the participant may at any time request the non-use of their research data by contacting the researcher responsible for this research project. In such an event, the information already obtained within the framework of this project will be kept as long as necessary to comply with regulatory requirements, but no new project will be carried out with the research data of the participant.

5. Commercialisation and intellectual property

5.1. Commercialisation

The Courtois NeuroMod database was created to help advance our knowledge of the human brain and artificial intelligence. The data from the Courtois NeuroMod database therefore have the main purpose of answering scientific questions. No sale of the data is allowed. On the other hand, it is understood that this data may be used by researchers to generate discoveries, which may themselves lead to commercial use.

5.2. Intellectual property

The Courtois NeuroMod bank retains all its intellectual property rights regarding its data. However, any result, product, service, process, patentable technology, or any work that may be subject to copyright, resulting from the use of the Courtois NeuroMod Bank, are the property of the research team that designed and implemented the scientific research project, independently of the Courtois NeuroMod team, and in accordance with the rules in force in their home institution. Provided that the Courtois NeuroMod databank retains its intellectual property on the data, it does not claim any intellectual property rights to original discoveries made by independent research teams using Courtois NeuroMod Bank data.