The brainstem and its interaction with the basal ganglia in Parkinson’s Disease

A Data Management Plan created using DMPonline.be

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Project abstract:

Deep brain stimulation (DBS) is routinely used to treat Parkinson's disease (PD) symptoms when medication is no longer sufficient. Despite decades of clinical practice, the physiological mechanism underlying DBS remains elusive and it fails to treat a range of gait-related symptoms. Research has mostly focused on the cortico-basal ganglia model but this has proven incomplete. Far less explored is the role of the brainstem nuclei connected to the basal ganglia, given the difficulty to access these nuclei in vivo. Given its involvement in gait impairments such as freezing-of-gait, a comprehensive approach to studying the brainstem may provide the key to successful treatment. With the advent of cutting-edge neuroimaging techniques and chronic wireless DBS recordings, we are at a turning point in understanding brainstem functioning. I will exploit these technological advances to address two research questions. First, what is the role of the brainstem's connection with the basal ganglia in the pathological oscillations that are characteristic of PD? Second, what are the pathophysiological changes associated with brainstem degeneration? To answer the former question, I will investigate the functional coupling between basal ganglia and the brainstem using cognitive paradigms that are known to evoke brainstem activity.To answer the latter, I will examine how neurophysiological markers of the basal ganglia-brainstem interaction evolve during the progression of PD pathology.

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1. Research Data Summary

List and describe all datasets or research materials that you plan to generate/collect or reuse during your research project. For each dataset or data type (observational, experimental etc.), provide a short name & description (sufficient for yourself to know what data it is about), indicate whether the data are newly generated/collected or reused, digital or physical, also indicate the type of the data (the kind of content), its technical format (file extension), and an estimate of the upper limit of the volume of the data.

				Only for digital data	Only for digital data	Only for digital data	Only for physical data
Dataset Name	Description	New or reused	Digital or Physical	Digital Data Type	Digital Data format	Digital data volume (MB/GB/TB)	Physical volume
		Please choose from the following options: • Generate new data • Reuse existing data	*Please choose from the following options:* • Digital • Physical	*Please choose from the following options:* • Observational • Experimental • Compiled/aggregated data • Simulation data • Software • Other • NA	*Please choose from the following options:* • .por, .xml, .tab, .csv,.pdf, .txt, .rtf, .dwg, .gml, … • NA	*Please choose from the following options:* • <100MB • <1GB • <100GB • <1TB • <5TB • <10TB • <50TB • >50TB • NA	
Electrophysiological recordings (EEG & LFP) - Shanghai Jiao Tong University School of Medicine, Affiliated Ruijin Hospital (China)	Electrophysiological recordings from Parkinson's disease, dystonia and epilepsy patients, including intracranial local field potential (LFP) data measured via deep brain stimulation (DBS) electrodes and EEG data.	Reused	Digital	Experimental	NA (multiple file types)	< 1TB	
Electrophysiological recordings (EEG & LFP) - KU Leuven	This dataset will be collected at UZ Leuven, patient recruitment is done by prof. Myles Mc Laughlin. The data is collected in the same fashion as was the case for the dataset from Ruijin Hospital.	New	Digital	Experimental	NA (multiple file types)	< 1TB	

EEG data healthy participants	For the development of new stimulation paradigms as well as the optimization of the ones already in use, EEG data of healthy subject is collected and processed.	New	Digital	Experimental	NA (multiple file types)	< 100 GB	
MR images	pre- and postoperative MR images are collected as part of the DBS therapy, to verify electrode implantation location. These images will be used to obtain exact DBS electrode locations.	Reused	Digital	Experimental	NA	< 100 GB	

If you reuse existing data, please specify the source, preferably by using a persistent identifier (e.g. DOI, Handle, URL etc.) per dataset or data type:

The dataset from Ruijin Hospital China was already collected by my co-supervisor Dr. Mansoureh Fahimi Hnazaee from the Wellcome Centre for Human Neuroimaging (University College London), and Dr. Cao Chunyan, from Shanghai Jiao Tong University School of Medicine, Ruijin Hospital. However no previous publications about this dataset have come out nor has it been used in other studies. The data processing agreement with Shanghai Jiao Tong University School of Medicine, Ruijin Hospital is in the making as well as the PRET application (reference: G-2023-7537).

Are there any ethical issues concerning the creation and/or use of the data (e.g. experiments on humans or animals, dual use)? Describe these issues in the comment section. Please refer to specific datasets or data types when appropriate.

- Yes, human subject data

Yes.

In the case of the dataset from Ruijin Hospital: The transfer of information from Ruijin Hospital to KU Leuven is covered by a Data Processing Agreement (approval still pending). A PRET application (reference: G-2023-7537) for the approval of the processing of this data at KU Leuven is also pending.

KU Leuven, healthy participants: The collection of this data is covered by an ethical approval granted by the Ethics Committee Research UZ / KU Leuven (reference: S62547).

KU Leuven, patient data: The ethical approval permitting the collection of this dataset has not yet been obtained.

Will you process personal data? If so, briefly describe the kind of personal data you will use in the comment section. Please refer to specific datasets or data types when appropriate.

- Yes

Yes. Besides EEG and intracranial LFP measurements, also pre/post implant CT/MRI scans will be collected, and basic clinical- and personal information, such as gender, age and dominant hand, shared.

Does your work have potential for commercial valorization (e.g. tech transfer, for example spin-offs, commercial exploitation, …)? If so, please comment per dataset or data type where appropriate.

- No

Not applicable.
In the case of the Chinese dataset: The division of IP rights between Ruijin Hospital and KU Leuven is stipulated in the Data Processing Agreement (reference: /, not yet finalized).

Do existing 3rd party agreements restrict exploitation or dissemination of the data you (re)use (e.g. Material/Data transfer agreements/ research collaboration agreements)? If so, please explain in the comment section to what data they relate and what restrictions are in place.

- Yes

The dissemination and exploitation of transferred data and of the obtained results are stipulated in the Data Processing Agreement (reference: /, not yet finalized).

Are there any other legal issues, such as intellectual property rights and ownership, to be managed related to the data you (re)use? If so, please explain in the comment section to what data they relate and which restrictions will be asserted.

- No

Not applicable.
In the case of the Chinese dataset: The division of IP rights between Ruijin Hospital and KU Leuven is stipulated in the Data Processing Agreement (reference: /).

2. Documentation and Metadata

Clearly describe what approach will be followed to capture the accompanying information necessary to keep data understandable and usable, for yourself and others, now and in the future (e.g., in terms of documentation levels and types required, procedures used, Electronic Lab Notebooks, README.txt files, Codebook.tsv etc. where this information is recorded).

Documentation accompanying each of the datasets listed in section 1 is kept in word documents, powerpoints detailing the analytical and procedural information, definition of variables, etc. and README.txt files in Github.

Will a metadata standard be used to make it easier to find and reuse the data? If so, please specify (where appropriate per dataset or data type) which metadata standard will be used. If not, please specify (where appropriate per dataset or data type) which metadata will be created to make the data easier to find and reuse.

- No

No metadata will be created for use by 3rd parties without prior approval of the responsible parties at Shanghai Jiao Tong University School of Medicine, Affiliated Ruijin Hospita and in compliance with the Data Processing Agreement (reference:) between Ruijin Hospital and KU Leuven.
Likewise, for data recorded at KU Leuven or received from UZLeuven, no metadata will be created without prior approval from UZLeuven's Ethical Committee and patient/healthy participant's consent.

3. Data storage & back-up during the research project

Where will the data be stored?

The pseudonymized data received by KU Leuven or recorded at KU Leuven will be stored on a secure, password-protected storage facility not accessible by external parties at the research unit.

How will the data be backed up?

Disk mirroring. The received data is a copy of the original data stored at Ruijin Hospital on a secure, password-protected computer, separate from the patient dossiers from which it is a partial excerpt.
Likewise, data received from UZLeuven will be stored on a secure, password-protected computer, separate from the patient dossiers from which it is a partial excerpt.
Likewise, data recorded at KU Leuven will be stored on a secure, password-protected computer.

Is there currently sufficient storage & backup capacity during the project? If yes, specify concisely.
If no or insufficient storage or backup capacities are available, then explain how this will be taken care of.

- Yes

Yes, the data is stored on a secure, password-protected storage facility not accessible by external parties.

How will you ensure that the data are securely stored and not accessed or modified by unauthorized persons?

The data received or recorded at at KU Leuven will be stored on a secure, password protected computer not accessible by external parties and on encrypted disks. Portable disks (e.g. USB sticks) will be encrypted as well.

What are the expected costs for data storage and backup during the research project? How will these costs be covered?

Storage resources at KU Leuven are covered by grants.

4. Data preservation after the end of the research project

Which data will be retained for at least five years (or longer, in agreement with other retention policies that are applicable) after the end of the project? In case some data cannot be preserved, clearly state the reasons for this (e.g. legal or contractual restrictions, storage/budget issues, institutional policies...).

After the end of the project, both the data received by KU Leuven from UZLeuven and Ruijin Hospital as well as the data generated at KU Leuven will be preserved for 10 years at KU Leuven, in as far as legal and contractual agreements apply.

Where will these data be archived (stored and curated for the long-term)?

Not applicable.

What are the expected costs for data preservation during the expected retention period? How will these costs be covered?

Storage resources at KU Leuven are covered by grants.

5. Data sharing and reuse

Will the data (or part of the data) be made available for reuse after/during the project? In the comment section please

explain per dataset or data type which data will be made available.

- No (closed access)
- Yes, in a restricted access repository (after approval, institutional access only, …)

As it concerns patient data, sharing with 3rd parties is only admissible after prior approval by Ruijin Hospital in compliance with the Data Processing Agreement, reference: /). In the case of the UZ Leuven patient data, as this also concerns patient data, sharing with 3th parties depends om prior approval from UZ Leuven's Ethical Committee and patient consent.

If access is restricted, please specify who will be able to access the data and under what conditions.

Prior approval from UZ Leuven's Ethical Committee and patient/participant's consent.when concerning UZLeuven/KU Leuven recorded data.

Are there any factors that restrict or prevent the sharing of (some of) the data (e.g. as defined in an agreement with a 3rd party, legal restrictions)? Please explain in the comment section per dataset or data type where appropriate.

- Yes, Privacy aspects
- Yes, Ethical aspects

Both datasets from Ruijin Hospital and UZ Leuven concern patient data and thus access needs to be restricted.

Where will the data be made available? If already known, please provide a repository per dataset or data type.

As it concerns patient data, sharing with 3rd parties is only admissible after prior approval by Ruijin Hospital in compliance with the Data Processing Agreement, reference:). In the case of the UZ Leuven patient data, as this also concerns patient data, sharing with 3th parties is restricted and pending approval from UZ Leuven's Ethical Committee and patient/participant's consent.

When will the data be made available?

As it concerns patient data, sharing with 3rd parties is only admissible after prior approval by Ruijin Hospital in compliance with the Data Processing Agreement, reference:). In the case of the UZ Leuven patient data, as this also concerns patient data, sharing with 3th parties is restricted and pending approval from UZ Leuven's Ethical Committee and patient/participant's consent..

Which data usage licenses are you going to provide? If none, please explain why.

Not applicable.

Do you intend to add a PID/DOI/accession number to your dataset(s)? If already available, you have the option to provide it in the comment section.

- No

/

What are the expected costs for data sharing? How will these costs be covered?

Not applicable.

6. Responsibilities

Who will manage data documentation and metadata during the research project?

Marc Van Hulle is responsible for the data received from Ruijin Hospital, in compliance with the Data Processing Agreement (reference: /) between Ruijin Hospital and KU Leuven, Myles McLaughlin for patient data recorded at UZLeuven, Marc Van Hulle for healthy participants data at KU Leuven .

Who will manage data storage and backup during the research project?

Marc Van Hulle is responsible for the secure, password-protected storage data at KU Leuven of the data received from Ruijin Hospital, as well as for the data generated at UZ Leuven.

Who will manage data preservation and sharing?

Marc Van Hulle

Who will update and implement this DMP?

Marc Van Hulle