Unraveling the neural network of breathing in myotonic dystrophy using fMRI

A Data Management Plan created using DMPonline

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Project abstract:

In this project, I will study neural control of breathing in patients with myotonic dystrophy type I. It will enrich existing knowledge in two areas. First, neural control of breathing is a very complex process that can operate either under an automatic brainstem network or voluntary cortical command. Current research related to the neural network of breathing is dominated by in vitro and in vivo animal studies, primarily rodents. This animal work greatly contributed to our understanding of control of breathing, but translation to humans is cumbersome. The sophisticated techniques used in animal studies include direct electrophysiological recording of neurons in the brainstem, immunohistochemistry and in vitro isolation of the brainstem. All of these techniques are impossible to apply in human studies. Instead in in vivo human studies it is only possible to measure the input (e.g. arterial oxygen and carbon dioxide concentrations) and output (e.g. respiratory muscle activity, breathing rate, tidal volume) of the respiratory neural system, whilst the actual controller (i.e the brain) remains a black box. In this project my aim is to fill this knowledge gap and open the black box of the brain. To this end, I will develop a novel concurrent breathing-fMRI method, as described in the research proposal. Second, myotonic dystrophy type I is the most common form of muscular dystrophy in adults and respiratory failure is a cardinal feature of the disease. The pathophysiology of respiratory failure in these patients is complex. Myotonic dystrophy is not only a neuromuscular disease, but also a multi-system disorder with abnormalities in the brain. Therefore, the question whether there is impaired central respiratory drive, besides respiratory muscle weakness, was explored in several studies. Many of these studies used the ventilatory response to carbon dioxide to demonstrate central involvement. Furthermore, there is evidence from post-mortem studies that there is a reduction in chemosensitive neurons in the arcuate nucleus. Overall, the consensus among the majority of studies is that respiratory failure is in part caused by a central failure, but the exact mechanism is not understood. In this project I will fill this knowledge gap by unraveling the mechanism for central respiratory failure in myotonic dystrophy using the advanced neuroimaging techniques that I will develop.

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1. General features of the project and data collection

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- The expert is connected to my department or institution (please explain his/hr expertise related to data stewardship)

Jessica Askamp - Data Steward at Donders Centre for Cognitive Neuroimaging
Mirjam Brullemans - Data Steward at Radboudumc
Both Jessica and Mirjam are dedicated data stewards connected to my research institute.

- Generate new data
- Exclusively quantitative data
- No, I will not be reusing or combining existing data
- No
- No, I am not working with 2 or more partners
- Yes (please specify)

n=25 healthy subjects
n=10 myotonic dystrophy patients

estimated data size: 100 Gb

- Documentation of the research process, including documentation of all participants
- Syntaxes
- Data documentation
- (Several versions of) processed data
- Raw data

Raw data from experimental procedures will be made available, including MRI (structural and functional) and biophysical signals.
Processed data, like dynamical causal modeling of fMRI data, will be made available,
Algorithms to reproduce processed data will be made available.
Documentation will be provided containing information about the data and experimental procedures.
Data sharing will only be made possible under the condition that it can be pseudonymized.

- Yes, I will make use of my institution's standard facilities for storage and backup of my data

Data will be stored in a project specific folder on a network attached storage that is password protected and behind a firewall. All data on the network storage system is backed up overnight to a tape robot located in another building on campus. The DCCN technical group oversees the automated backup process and, if necessary, restoration.

2. Legislation (including privacy)

- The Wet Medisch-Wetenschappelijk Onderzoek met Mensen (WMO, or Medical Research (Human Subjects) Act) applies to my project; I will have it reviewed by a Medical Research Ethics Committee. In addition I will comply with the Kwaliteitsborging Mensgebonden Onderzoek (Quality Assurance for Research Involving Human Subjects)
- Yes, I will involve human subjects in my research. I will comply with the Algemene Verordening Gegevensbescherming (AVG)

- Yes, and this informed consent allows for the reuse of data (note that in the Code of Conduct for Medical Research, 'reuse' is also referred to as 'further use')

- Yes, the data will be pseudonymised. (please explain how this will be done, and by which organisation) and

I will use PIMS (Participant Identity Management System; seehttps://pims.radboudumc.nl/) for deidentification of patient (traceable) personel information.

- Yes

3. Making data findable

- Yes, it can be found through an online (metadata) catalogue or web portal (please specify)

Data will be shared in the Donders repository (https://data.donders.ru.nl).
The persistent identifier of the data sharing collection in the Donders repository is available once that data collection has been created (in the future). However the persistentID will only be *active* once the data collection has been published (e.g. at paper publication).

Metadata of published collections in the Donders Repository can be found through NARCIS.

- Yes, I will use a generic metadata scheme (please specify)

Minimum Information about an fMRI Study (MIfMRI): https://fairsharing.org/FAIRsharing.s3swh2
Data collection metadata follows Dublin Core and DataCite standards.
Where possible, domain specific standard vocabularies (SfN, MeSH, CogPo) will be used to describe the collection contents.

- Yes, in addition to the DOI code I will be using another persistent identifier (please specify)

At the Donders Repository a persistent identifier of Handle.Net Registry is used.

4. Making data accessible

- No (please explain)

Data will be accessible once the data collection has been published (e.g. at paper publication).

- No, there will be access restrictions to my data collection (please explain)

In line with privacy legislation, the Radboud University (security officer) and local ethical committee require that users of these data publications can be identified (e.g. in case of violation of a Data Use Agreement). Therefore, potentially identifiable data are shared under a specific Data Use Agreement that requires authentication in the Donders Repository to download these data sets.
link: https://data.donders.ru.nl/doc/dua/RU-DI-HD-1.0.html

- Yes, my institution employs internationally available terms of use

link: https://data.donders.ru.nl/doc/dua/RU-DI-HD-1.0.html

- Other (please explain)
- Collaboration in using the data set, including agreements on publication and authorship
- Whether or not the data set may be linked with another data set (for reasons of privacy)

link: https://data.donders.ru.nl/doc/dua/RU-DI-HD-1.0.html

5. Making data interoperable

- Yes (please specify)

Neuroimaging: BIDS format
Biophysical data: BioPac (.acq-files)
Coding: Matlab (m-files)

- Yes, metadata standard (please specify)

SNOMED CT

- Yes, the participants have given their permission for reuse of the data, and the data have been pseudonymised

6. Making data reusable

- I will document the software used in the course of the project (please specify)
- I will perform quality checks on the data to ensure that they are complete, correct and consistent (please explain)
- I will document the research process (please explain)

Castor EDC will be used for capturing research data, which includes quality checks on the data.
I will add readme files in the data repository to each subfolder for interpretation of the folder content.
I will add comments to software scripts to in enhance interpretation.

- No

- Yes (please specify)

100 Gb estimated.

- Yes, and this archive meets certification criteria and intends to get certified (please explain how your data will remain accessible and reusable in the long term)

https://data.donders.ru.nl/
Currently, the CTS certification procedure is running.

- Yes, in accordance with VNSU guidelines (please specify the number of years)

10 years

- Unknown (please explain)

There are no project-specific costs for long-term archiving and for sharing of published data, these are included in the project overhead and/or lab costs.

- Yes (please elaborate)

There are no project-specific costs for long-term archiving and for sharing of published data, these are included in the project overhead and/or lab costs.