Plan Overview

A Data Management Plan created using DMPonline

Title: Unraveling the neural network of breathing in myotonic dystrophy using fMRI

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Affiliation: Radboud University Medical Center (Radboudumc)

Funder: ZonMw (Nederlands)

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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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Unraveling the neural network of breathing in myotonic dystrophy using fMRI

1. General features of the project and data collection

1.1 Project leader contact details

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1.2 I have composed my DMP with the assistance of a data stewardship (or management) expert. List his or her name, function, organisation/department, phone number and email address.

- 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.

1.3 In collecting data for my project, I will do the following:

- Generate new data

1.4 In my research, I will use:

- Exclusively quantitative data

1.5 I will be reusing or combining existing data, and I have the owner's permission for that.

- No, I will not be reusing or combining existing data

1.6 In collecting new data, I will be collaborating with other parties.

- No

1.7 I am a member of a consortium of 2 or more partners. Clear arrangements have been made regarding data management and intellectual property. (also consider the possible effect of changes within the consortium on issues of data management and intellectual property)

- No, I am not working with 2 or more partners

1.8 I can give an estimate of the size of the data collection; specifically, the number of participants or subjects (“n=”) in the collection and its size in GB/TB

- Yes (please specify)

n=25 healthy subjects
n=10 myotonic dystrophy patients

estimated data size: 100 Gb

1.9 The following end products I will make available for further research and verification (please elaborate briefly)

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

1.10 During the project, I will have access to sufficient storage capacity and sites, and a backup of my data will be available. (please elaborate briefly)

- 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)

2.1 I will be doing research involving human subjects, and I am aware of and compliant with laws and regulations concerning privacy sensitive data.

- 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)

2.2 I will be doing research involving human subjects, and I have (a form of) informed consent from the participants for collecting their data.

- 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’)

2.3 I will be doing research involving human subjects, and I will protect my data against misuse.

- 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; see https://pims.radboudumc.nl/) for deidentification of patient (traceable) personel information.

2.4 I will stick to the privacy regulations of my organisation

- Yes

3. Making data findable

3.1 The data collection of my project will be findable for subsequent research. E.g., on a catalogue, a web portal, or through the search enginge of the repository (note: this is key item 3, which you should report to ZonMw at the end of your project).

- 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.

3.2 I will use a metadata scheme for the description of my data collection (note: this is key item 7, which you should report to ZonMw at the end of your project).

- 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.

3.3 I will be using a persistent identifier as a permanent link to my data collection (note: this is key item 1, which you should report to ZonMw at the end of your project).

- 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

4.1 Once the project has ended, my data will be accessible for further research and verification.

- No (please explain)

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

4.2 Once the project has ended, my data collection will be publicly accessible, without any restrictions (open access).

- 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

4.3 I have a set of terms of use available to me, which I will use to define the requirements of access to my data collection once the project has ended (please provide a link or persistent identifier; also note that this is a key item 4, which you should report to ZonMw at the conclusion of your project).

- Yes, my institution employs internationally available terms of use

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

4.4 In the terms of use restricting access to my data, I have included at least the following:

- 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)
- Other (please explain)

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

5. Making data interoperable

5.1 I will select a data format, which will allow other researchers and their computers (machine actionable) to read my data collection (note: this is key item 5, which you should report to ZonMw at the end of your project).

- Yes (please specify)

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

5.2 I will select a terminology for recording my data (e.g., code, classification, ontology) that allows my dataset to be linked or integrated with other datasets (note: this is key item 6, which you should report to ZonMw at the conclusion of your project).

- Yes, metadata standard (please specify)

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5.3 I will be doing research involving human subjects, and I have taken into account the reuse of data and the potential combination with other data sets when taking privacy protection measurements.

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

6. Making data reusable

6.1 I will ensure that the data and their documentation will be of sufficient quality to allow other researchers to interpret and reuse them (in a replication package).

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

6.2 I have a number of selection criteria, which will allow me to determine which part of the data should be preserved once the project has ended. (see also question 1.9 and 6.1)

- No

6.3 Once the project has ended and the data have been selected, I can make an estimate of the size of the data collection (in GB/TB) to be preserved for long-term storage or archival.

- Yes (please specify)

100 Gb estimated.

6.4 I will select an archive or repository for (certified) long-term archiving of my data collection once the project has ended. (note: this is a key item, which you should report to ZonMw at the conclusion of your project)

- 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.

6.5 Once the project has ended, I will ensure that all data, software codes and research materials, published or unpublished, are managed and securely stored. Please specify the period of storage.

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

10 years

6.6 Data management costs during the project and preparations for archival can be included in the project budget. These costs are:

- 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.

6.7 The costs of archiving the data set once the project has ended are covered.

- 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.