11PP224N: Understanding somatosensory deficits and the potential of targeted therapy to improve upper limb function in children with unilateral cerebral palsy: a behavioral and neurological approach

A Data Management Plan created using DMPonline.be

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Project abstract:

Unilateral cerebral palsy (uCP) is a lifelong disorder resulting from a lesion in the developing brain. Besides motor impairments, up to 90% of these children also have somatosensory deficits in the upper limb. As somatosensory information is of utmost importance for coordinated upper limb movements and motor learning, somatosensory deficits may hamper effective use of the impaired upper limb in bimanual daily life activities. However, an in-depth understanding of somatosensory deficits, their relation to bimanual motor function and knowledge on brain dysfunctions underlying somatosensory deficits, are still lacking. Yet, this information is crucial to improve current upper limb therapies for children with uCP. Therefore, in this project, we will first perform an in-depth investigation of deficits in different modalities of somatosensation and their influence on bimanual motor function, using clinical assessments and advanced robotics. Secondly, we will examine neurological correlates underlying somatosensory deficits, using neuroimaging and innovative brain analysis techniques. Lastly, we will investigate the clinical and neuroplastic effects of a targeted therapy approach focused on somatosensation, i.e. somatosensory discrimination therapy. Hence, the findings of this project will result in an advanced understanding of somatosensory deficits in children with uCP: from fine-grained assessments to optimization of individualized upper limb therapy.

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DPIA

DPIA

Have you performed a DPIA for the personal data processing activities for this project?

- Not applicable

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GDPR

GDPR

Have you registered personal data processing activities for this project?

- Not applicable

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Application DMP

Questionnaire

Describe the datatypes (surveys, sequences, manuscripts, objects …) the research will collect and/or generate and /or (re)use. (use up to 700 characters)

We will collect primary, quantitative, experimental and observational data, as well as secondary demographical data from the medical record (University Hospitals Leuven).
Physical data, including informed consent forms, questionnaires and notes during assessments, will be digitalized (.pdf) after the assessments.
Digital data further include: (1) Instrument specific data from clinical assessments (.txt,
.xlsx, .csv, .pdf and a software specific format), with extracted numerical data saved as .xlsx; (2) Demographical data from questionnaires (.pdf) and medical records (.xlsx); (3) Movie data from one clinical assessment (.MP4); and (4) Neuroimaging data from brain MRI scans (DICOM files).

Specify in which way the following provisions are in place in order to preserve the data during and at least 5 years after the end of the research? Motivate your answer. (use up to 700 characters)

Prof Feys (PI, KU Leuven) is responsible for data storage and preservation.
During the PhD fellowship, all pseudonymized digital data will be stored on the REDCap platform that can only be accessed by using two-factor authentication (budget foreseen by PI). The patient identifier record (PIR) will be stored separately with password protected access for prof Feys.
Once the fellowship has ended, relevant research data will be archived on a secured network at KU Leuven (K-drive), which is password protected and includes strict access regulations. This network is funded for 50% by the Group of Biomedical Sciences and for 50% by the Department of Rehabilitation Sciences.

What's the reason why you wish to deviate from the principle of preservation of data and of the minimum preservation term of 5 years? (max. 700 characters)

We will not deviate from the principle of preservation of data and the minimum preservation term of 5 years.
More specifically, clinicians from the University Hospitals Leuven who are treating the patient will have access to their structural MRI scans and video recording (clinical assessment). To this aim, the video will be saved on the secure network of the University Hospitals Leuven. These data will be saved according to the legal term of the medical file, namely a minimum of 30 years. Nevertheless, the parents of the child can always indicate if they do not want this.

Are there issues concerning research data indicated in the ethics questionnaire of this application form? Which specific security measures do those data require? (use up to 700 characters)

As we are collecting personal data of minors, additional attention should be given to security measures to ensure safe data management. All collected data will be stored pseudonymized in REDCap, which includes appropriate access control. The patient identifier record (PIR) will be kept separately on the secured J-drive of KU Leuven and access is strictly regulated. Furthermore, no unique combinations of data will be collected to avoid that the identity of participants can be identified.

Which other issues related to the data management are relevant to mention? (use up to 700 characters)

The ethical committee of UZ Leuven/KU Leuven is aware of the data collection and storage procedure for WP1 (S-number of the study: S62906). GDPR-regulations will be considered in all steps of data management. The REDCap platform is managed by KU Leuven/UZ Leuven. It ensures automatic back-ups and includes a complete logbook of data consultation and editing. Lastly, it also contains a secure data transfer application ('Send-it') and private build-in messenger, which facilitates secure communication regarding data among researchers.

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FWO DMP (Flemish Standard DMP)

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
ICF	Informed consent forms, informed assent forms	☒ Generate new data ☒ Reuse existing data	☒ Digital ☒ Physical	☐ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☒ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☒ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☐ other: ☐ NA	☒ < 100 MB ☐ < 1 GB ☐ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	Printed papers (4 large ring binders)
Kinarm	Numerical data related to bimanual performance and proprioception, collected with the Kinarm Exoskeleton	☒ Generate new data ☒ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☒ .csv ☐ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☒ other: software specific format (.c3d) ☐ NA	☐ < 100 MB ☐ < 1 GB ☒ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/
BOT	Three-dimensional motion analysis of both upper limbs, collected during the performance of the box opening task	☒ Generate new data ☒ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☒ .csv ☐ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☐ other: ☐ NA	☐ < 100 MB ☐ < 1 GB ☒ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/
AHA	Video recording and numerical data, acquired during the Assisting Hand Assessment	☒ Generate new data ☒ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☐ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☒ other: .xlsx, .mp4 ☐ NA	☐ < 100 MB ☐ < 1 GB ☐ < 100 GB ☒ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/
CHEQ	Survey data from the Children's Hand-use Experience Questionnaire	☒ Generate new data ☒ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☒ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☐ other: ☐ NA	☒ < 100 MB ☐ < 1 GB ☐ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/

TPT	Numerical data, acquired during the Tyneside Pegboard Test	☒ Generate new data ☒ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☒ .csv ☐ .pdf ☒ .txt ☐ .rtf ☐ .dwg ☐ .gml ☐ other: ☐ NA	☒ < 100 MB ☐ < 1 GB ☐ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/
Clinical_-somatosensory	Numerical data acquired during clinical examination of somatosensory function (Semmes-Weinstein Monofilaments, stereognosis, two point discrimination, texture discrimination, proprioception)	☒ Generate new data ☒ Reuse existing data	☒ Digital ☒ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☒ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☒ other: .xlsx ☐ NA	☒ < 100 MB ☐ < 1 GB ☐ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	Printed papers (4 large ring binders)
ETH MIKE	Numerical data related to proprioception, collected with the ETH MIKE robot	☒ Generate new data ☒ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☐ .pdf ☒ .txt ☐ .rtf ☐ .dwg ☐ .gml ☒ other: .xlsx ☐ NA	☐ < 100 MB ☐ < 1 GB ☒ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/
MRI	Brain MRI scan and related numerical data	☒ Generate new data ☒ Reuse existing data	☒ Digital ☐ Physical	☐ Observational ☒ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☐ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☒ other: .xlsx, .dcm ☐ NA	☐ < 100 MB ☐ < 1 GB ☐ < 100 GB ☐ < 1 TB ☐ < 5 TB ☒ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/
General_data	Treatment history and general patient characteristics from medical record and based on parental questionnaires	☒ Generate new data ☒ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☒ Other: reports ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☒ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☒ other: .xlsx ☐ NA	☒ < 100 MB ☐ < 1 GB ☐ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/
MACS	Manual Ability Classification System	☒ Generate new data ☒ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☐ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☒ other: .xlsx ☐ NA	☒ < 100 MB ☐ < 1 GB ☐ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/
Sense	Video recording of therapy sessions of the intervention group and numerical data related to treatment fidelity	☒ Generate new data ☐ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☐ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☒ other: .xlsx, .mp4 ☐ NA	☐ < 100 MB ☐ < 1 GB ☐ < 100 GB ☐ < 1 TB ☐ < 5 TB ☒ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/

GAS	Video recording of goal performance and related numerical data	☒ Generate new data ☐ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☒ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☒ other: .mp4 ☐ NA	☐ < 100 MB ☐ < 1 GB ☐ < 100 GB ☒ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/
COPM	Transcript of semi-structured interview	☒ Generate new data ☐ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☒ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☐ other: ☐ NA	☒ < 100 MB ☐ < 1 GB ☐ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/
CBCL	Survey data from Child Behavioral Checklist	☒ Generate new data ☐ Reuse existing data	☒ Digital ☐ Physical	☒ Observational ☐ Experimental ☐ Compiled/ aggregated data ☐ Simulation data ☐ Software ☐ Other ☐ NA	☐ .por ☐ .xml ☐ .tab ☐ .csv ☒ .pdf ☐ .txt ☐ .rtf ☐ .dwg ☐ .gml ☐ other: ☐ NA	☒ < 100 MB ☐ < 1 GB ☐ < 100 GB ☐ < 1 TB ☐ < 5 TB ☐ < 10 TB ☐ < 50 TB ☐ > 50 TB ☐ NA	/

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:

Through previous research (FWO project, G0C4919N), we already established a cross-sectional database on bimanual outcomes (Kinarm, BOT, AHA, CHEQ, TPT) and somatosensory measures of upper limb function (Kinarm, ETH MIKE, clinical_somatosensory) in children with unilateral cerebral palsy and typically developing children. This database contains data, collected at one timepoint, for a group of 50 children with unilateral cerebral palsy and 59 typically developing children.
At this point there is not yet a persistent identifier for this database, however, a DOI number will be allocated at a later timepoint as described below.

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

We will conduct research experiments on humans, more specifically on children and adolescents. The study activities of WP1 and WP2 were approved by the Ethics Committee Research UZ/KU Leuven (S-number WP1: S62906, S-number WP2: S67467).

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

Two types of personal data will be collected, based on the medical file of the participants and parental questionnaires:
- Personal data for contact purposes (e.g., name, address, phone number, e-mail), which will not be used in any further analysis. Participants, their parents and the treating physician will be asked whether this information can be used for contact purposes.
- Personal data for research purpose, consisting of socio-demographical data (e.g., sex, date of birth, handedness) and data concerning medical status (e.g., disease severity, medication intake, birth weight, gestational age, functionality).

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

/

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.

- No

/

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

/

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).

All data will be coded. The following documents can be used to understand and use the data:

- Documentation approved by the Ethics Commission: description of study protocol (.pdf) and related documents (.pdf)
- Informed consent and assent forms: original blank copies (.pdf) and signed hardcopies (printed paper)
- Experimental protocols: description how the data are collected and generated (software, materials, set-up, settings (.docx/.pdf)) and how data are processed (software, protocol, guidelines, … (.docx/.pdf/.xlsx))
- Participant data collection form: printed papers containing personal data (e.g., age, grade of involvement, handedness) and a short overview of assessment results. The data collection forms describe measurement information for each participant, whereby the participant's identity is coded.
- Raw experimental data: folders with original digital data in software-specific files (.csv, .xlsx or printed documentation (.pdf))
- Processed data: uploaded into REDCap and stored in spreadsheets (.xlsx or .csv)
- REDCap codebook: provides information on the structure, content and build-up of the REDCap project (.pdf).
- Patient identifier record (PIR): name of included participants, and participant study code (.xlsx). This patient identifier record is the only document that provides the link between the individual study code and the participant's identity
- Randomization list: digital document used for stratified randomization (.xlsx). This document contains information regarding the different stratification factors for each participant (i.e., age group, MACS, level of somatosensory impairment), whereby the participant's identity is coded.

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

Except for MRI (i.e., NifTi), no metadata standard will be used.
Observational data will be managed via REDcap, which ensures efficient safe storage and keeps track of data use and associated extra processing related to each experimental step. In REDCap, the Data Dictionary is a spreadsheet (.csv) containing the metadata used to construct the different data collection instruments and fields.

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

Where will the data be stored?

Raw and processed data will be stored per assessment. Digital data files will be stored on secure KU Leuven servers and networks (J-drive: GBW-0328_Pediatrics, L-drive: GBW-0103_eNRGy) and REDCap. Hard copies of the informed consent and assent forms and data collection forms are kept in locked cabinets in the desk of the PI (prof. dr. Hilde Feys).
Access is provided to the PI's of the project of KU Leuven and UHasselt and the closely involved researchers.

How will the data be backed up?

KU Leuven servers and networks are backed up automatically, based on the following regime:

- An hourly backup, the last 6 versions of which are saved
- A daily backup, the last 7 versions of which are saved
- A weekly backup, the last 6 versions of which are saved
- Data restoration can further be performed, upon request.

Digital data automatically stored on specific acquisition laptops during data collection (e.g., Kinarm, ETH MIKE, BOT), will be manually transferred via an external hard drive to the secure KU Leuven servers. Afterwards, data will be deleted from the external hard drive.

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, sufficient storage and backup capacity is provided on the KU Leuven servers and networks. The REDCap platform is also hosted on dedicated KU Leuven data servers, ensuring sufficient capacity for data storage.

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

Hard copies of the informed consent and assent forms and data collection forms are kept in locked cabinets in the desk of the PI.
Access to the KU Leuven servers is u-number and password controlled. Access control is further regulated by the PI of KU Leuven (prof. dr. Hilde Feys), access is provided to the PI's of the project of KU Leuven and UHasselt and the closely involved researchers. The PIR will be stored on the personal, password-secured KU Leuven network of the PI and the PhD-researcher, ensuring strictly regulated access to the personal information of the participants.
The REDCap platform can only be accessed by specific team members, by using two-factor authentication. Access control will be regulated by the PI of KU Leuven (prof. dr. Hilde Feys).

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

We estimate to collect approximately 15TB of data, which will be divided over the KU Leuven servers and networks (J-drive: GBW-0328_Pediatrics, L-drive: GBW-0103_eNRGy), REDCap and an external hard disk. Data storage will cost around €500 for each year of this project. This will be funded by left over budgets of the PI of KU Leuven (prof. dr. Hilde Feys) and the bench fee of this FWO fellowship.

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...).

All processed digital data will be retained for the minimum preservation term of 30 years after the end of the project.

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

The digital data will be archived on the password-secured network of the KU Leuven network (K-drive) and/or an external hard disk controlled by the PI of KU Leuven. Hard copies (e.g., Informed consent and assent forms, data collection forms) are kept in locked cabinets in the desk of the PI.

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

After the project has ended and all data processing has been performed, the REDCap platform will be kept. This will be financed using budgets from new projects to sustain storage facilities for the research team. All data that was stored on the KU Leuven networks and servers will be transferred to an external hard disk that will be password protected and stored in a locked cabinet in the desk of the PI. The cost for this hard disk will be covered by the bench fee of this FWO fellowship.

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.

- Yes, in a restricted access repository (after approval, institutional access only, …)

Where possible according to the ethical regulations, processed data that was used to perform statistical analyses will be available via the 'KU Leuven Research Data Repository' and upon reasonable request by e-mail, both during the project as well as after the end of the project. According to the GDPR regulations, restricted data access will be applied, because of the publication of pseudonymized data. Decoded data and personal identifiers (e.g., date of birth, contact details, address,…) will never be shared.

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

Data will only be made available to other researchers, after a Data transfer agreement has been developed in collaboration with LRD.

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, Ethical aspects

Existing data collected during an earlier FWO project (G0C4919N) will be reused within this FWO fellowship.
For this existing data, not all parents of participants provided informed consent to share the data with other (academic) partners for other than described in the study goals. Therefore, legal restrictions prevent sharing the full dataset, containing data of 50 children with unilateral cerebral palsy and 59 typically developing children. From this existing dataset, data of 39 children with unilateral cerebral palsy and 50 typically developing children will be uploaded in the ‘KU Leuven Research Data Repository’.
For data that will be newly collected within this FWO fellowship, no ethical aspects restrict sharing of research data with academic partners. Since all parents of participants will be asked to provide consent for data sharing with academic partners via the informed consent form. The full dataset of newly collected data, which is expected to consist of data from 50 children with unilateral cerebral palsy and 36 typically developing children, will be uploaded in the ‘KU Leuven Research Data Repository’.

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

The data will be made available on KU Leuven Data Research Repository.

When will the data be made available?

Upon publication of the results in a scientific journal.

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

The 'Custom KU Leuven license' will be selected. This means that the dataset is fully-restricted and agreements should be made before actual data sharing.

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.

- Yes

Not yet available

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

50GB of data can be shared on KU Leuven Research Data Repository, without any cost for the researcher sharing the data. We except that this capacity will not be exceeded.

6. Responsibilities

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

The PhD researcher (Lize Kleeren) associated with this project will be responsible for data documentation and metadata, under supervision of the KU Leuven PI (prof. dr. Hilde Feys).

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

Data management, storage and back up will be performed by the PhD researcher (Lize Kleeren) associated with this project, under supervision of the KU Leuven PI (prof. dr. Hilde Feys).

Who will manage data preservation and sharing?

Data preservation and sharing will be managed by the KU Leuven PI (prof. dr. Hilde Feys).

Who will update and implement this DMP?

This DMP will be updated by the PhD research associated with this project (Lize Kleeren), under supervision of the KU Leuven PI (prof. dr. Hilde Feys).