

Belgian Language in Autism Study

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)

New data will be collected experimentally. No existing data will be used.

We will collect the following data from the participants and their parents:

- informed consent: either on Redcap, immediately online (preferred option) or on paper (+ digital (scanned) version (pdf))
- observation sheet per time moment: both on paper and digital in Redcap. Here we will keep track of date and time of testing + relevant observations for quality control of the collected data
- diagnostic report: to check the diagnosis of the participating children, we ask parents for a copy of the diagnostic report. This will be collected on paper or digital (pdf or docx)
- questionnaires: digital surveys in Redcap. If parents are not able to fill out the questionnaires online (at home or during the test session on a tablet that is provided by the testers), we will give them paper versions of the questionnaires.
- administration and recording of behavioural tests: On paper, digital in Redcap and video recording (to be able to score certain tests afterwards, for coding of relevant behaviours and for quality control)
- administration and recording of clinical, experimental and parent-child observations: video recording
- administration and recording of naturalistic language productions at home: audio recording and transcriptions
- administration and recording of different EEG paradigms, including resting state, mirror neuron activity, statistical learning, response to the own name and attention to eyes and mouth: EEG-data and video recording
- administration and recording of sleep and day-night cycle (incl. movement) with actigraph + sleep diary (Redcap)
- information on collection and analyses of these data will be registered in Redcap

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)

1. Designation of responsible person (If already designated, please fill in his/her name.)

The principal investigators at each site will be responsible for the preservation of the data (KUL Ilse Noens; UGent Herbert Roeyers; ULB Mikhail Kissine).

Prof. dr. Mikhail Kissine can be contacted via email: mikhail.kissine@ulb.be

Prof. dr. Herbert Roeyers can be contacted via email: Herbert.Roeyers@UGent.be

Prof. dr. Ilse Noens can be contacted via email: ilse.noens@kuleuven.be

2. Storage capacity/repository

- during the research
- after the research

Raw electronic data (e.g., video/audio recordings) will be stored by each research unit at each site on a secured password-protected (network) drive and on a Sharepoint, shared by the consortium members. Only the researchers at the site involved in the project will have access to the unanonymised data. Data will always be saved with a pseudocode.

Also researchers in the work packages that are working with specific data (e.g., Redcap data, video or audio recordings) will have access to this data, to which a pseudocode has been assigned.

Raw unanonymized paper data (e.g., informed consents, personal information survey) will be stored at each site in a locked closet. On all test administration sheets and other documents the pseudocode will be used.

Processed pseudonymised data (e.g., standardized scores, video/audio transcripts) will be stored at each site on a secured (network) drive and on Redcap.

All pseudonymised and processed data will be kept for a duration of 5 years after the end of the study.

After the end of the project, the data specified above will be kept at each site on the shared password-secured network drive. The data will also still be shared in a pseudonymized way with the consortium members on Redcap and Sharepoint as specified above. The data should be shareable to allow the other researchers/sites to keep access and if involved researchers leave the university after the end of the project.

After the retention period of 5 years, the data will be destroyed.

We understand that there is a risk for privacy breach in the use of video and audio material. The procedure for sharing these data is as follows:

Sharing data within the consortium

- Not all video and audio recordings will be shared. There are different reasons for sharing data:
 - Data quality control: at regular time points the responsible researcher for a work package will be able to consult a selection of videos for quality control (administration and scoring). We try to limit this by also doing quality checks during visits across sites or by teams.
 - Analyses of the data:
- - All data of the imitation and joint attention tasks is shared through Sharepoint with Hanna Van de Vyver and prof. Herbert Roeyers (UGent), as they are working on this WP.
 - All parent-child interaction is shared through Sharepoint with Ines Brys and prof. Ilse Noens (KU Leuven) and co-supervisor prof. Petra Warreyn (UGent) (scoring and potentially language examination).
 - The videos of these two WP are needed for coding the interaction. Only trained persons are able to code these tasks/interactions. We cannot blur the videos as facial expression and eye contact is important for the coding.
 - In addition, all audio data will be transferred to KU Leuven and ULB for linguistic analyses (WP of Klaartje Vertongen and Federica Beccaria, with supervisors prof. Inge Zink and prof. Mikhail Kissine).
 - Videos of the EEG administrations are shared through Sharepoint with Anouk Matthys and Marine Petit (EEG working group, with supervisors prof. Roeljan Wiersma and prof. Arnaud Destrebecqz) to be able to code attention to the screen.
- - Data access to video and audio material will be limited in time. Only for the time needed to code the data, access will be granted.
 - Before access to the video material is granted, each PhD student writes a proposal with their research questions and a list of the specific data needed to answer these research questions. Only after approval by the promoters of the study, access is granted, following the agreements stated above.
 - This procedure is also used for access to other data (saved on redcap).

Destroying video and audio recordings after coding/transcription/scoring

- As explained above, data access will be limited in time. Only for the time needed to code the data, access will be granted.
- After quality control is warranted and the coding/transcription/scoring is completely finished, video and audio recordings will be destroyed. Awaiting the final coding/transcription/scoring, access is again restricted to the local sites.

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)

Not applicable. Data will be kept for 5 years after the end of the study.

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)

Data of children with autism will be collected.

Ethical approval will be obtained from the dedicated ethical committees at each site (ULB, KUL, UGent). Parents of participants will be asked to sign an informed consent form in order to enroll their child in the study.

All identifiable information (name, e-mail address, phone number, address) will be kept on a separate file from the collected data. Each participant will receive a random pseudonymising identifier when entering the study and all collected data will be stored under this identifier only. The data at each site will be accessible only to those directly involved in the study. Each site will be able to grant access to researchers from other sites once the data has been completely pseudonymised and (for some tests) processed.

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

/

Belgian Language in Autism Study

GDPR

GDPR

Have you registered personal data processing activities for this project?

- Yes

Belgian Language in Autism Study

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.

We will collect new data experimentally for this project. The project is divided into 8 scientific work packages and each involve the creation of new data. Data will be collected at several time points over the course of 24 months following participants' enrollment in the study. T1 refers to the moment when participants enter the study; T2 is 12 months later, and T3 is 24 months later. The type, format and volume of the data that will be collected for each scientific work package is summarized in the table below.

No existing data will be used.

Work package 1: Environment & joint engagement - Ines

- Parent-child interactions: T1, T2, T3

| Type | Format | Volume (per timepoint) |
|-----------------|--------|------------------------|
| video recording | .mp4 | 60 GB |
| scoring | .xlsx | 7 MB |

- Questionnaires important for this work package are: the Parental Behavior Scale for Toddlers, the Parenting Stress Index (short version), the Social Responsiveness Scale for Adults, and self-constructed questionnaires on general information about the child, language, and intervention history. Parents will fill these out directly in Redcap.

Work package 2: Naturalistic language (Flemish) & symbol understanding - Klaartje

- Audio recordings of naturalistic language: every 6 months (5 times in total)

| Type | Format | Volume |
|-----------------|--------|--------|
| audio recording | .wav | 540 GB |
| transcriptions | .txt | 31 MB |

- ComFor-2: T1, T2, T3

| Type | Format | Volume |
|-------------------------|----------|--------|
| video recording | .mp4 | 60 GB |
| paper scoring booklet | on paper | / |
| scan of scoring booklet | .pdf | 300 MB |

- Doll house: T1, T2, T3

| Type | Format | Volume |
|-------------------------|----------|--------|
| video recording | .mp4 | 60 GB |
| paper scoring booklet | on paper | / |
| scan of scoring booklet | .pdf | 300 MB |

- Questionnaires important for this work package are: Communication and Symbolic Behavior Scales DP Caregiver. Parents will fill these out directly in Redcap

Work package 3: Joint attention & imitation - Hanna

- ESCS: T1, T2, T3

| Type | Format | Volume (per participant per timepoint) |
|-----------------------------|---------------|--|
| video recording | .mp4 | 2 GB |
| ESCS coded | .odx .xlsx | 200 kB |
| Observation form for coding | .docx | 20 kB |

- Unstructured Imitation Assessment: T1, T2, T3

| Type | Format | Volume (per participant per timepoint) |
|-----------------|----------|--|
| video recording | .mp4 | 2 GB |
| Paper scoring | On paper | / |
| scoring | .xlsx | < 1 MB |

- Preschool Imitation and Praxis Scale: T1, T2, T3

| Type | Format | Volume (per participant per timepoint) |
|-----------------|----------|--|
| video recording | .mp4 | 2 GB |
| Paper scoring | On paper | / |
| scoring | .xlsx | < 1 MB |

- Verbal imitation: T1, T2, T3

| Type | Format | Volume (per participant per timepoint) |
|-----------------|----------|--|
| video recording | .mp4 | 500 MB |
| Paper scoring | On paper | / |
| scoring | .xlsx | < 1 MB |

- Questionnaire:

Item 21 & item 45 of 'Social Responsiveness Scale': T1, T2, T3 (Redcap)

Work package 4: Mirror neuron system & resting state synchronization - Anouk

- EEG recordings of mirror neuron system activity: T1

| Type | Format | Volume (per participant) |
|-----------------|----------------------------|--------------------------|
| raw data | .eeg, .vhdr, .vmrk | 300 MB |
| processed data | (files from BVA) .excel | 35 MB |
| Video recording | .mp4 | 4 GB |

Work package 5: Naturalistic language (French) & foreign language learning - Federica

- Audio recordings of naturalistic language: every 6 months

| Type | Format | Volume |
|------------------|--------|--------|
| Audio recordings | .wav | 360 GB |
| transcriptions | .txt | 20 MB |

Work package 6: Sleep - Clara

- One-week recordings of body movements during sleep: T1, T2, T3

| Type | Format | Volume |
|------------|--------|--------|
| Recordings | .agd | 300 GB |

Work package 7: Statistical learning - Marine

EEG recordings of cerebral activity during a visual statistical learning paradigm

| Type | Format | Volume |
|--------------|-------------------|--------|
| eye tracking | .png, .csv., .txt | 45 GB |

Work package 8: General child characteristics

- Nonverbal IQ (SON-R): T1, T3

| Type | Format | Volume |
|-------------------------|----------|--------|
| video recording | .mp4 | 150 GB |
| paper scoring booklet | on paper | / |
| scan of scoring booklet | .pdf | 200 MB |

- receptive and expressive language (Bayley/CELF-p+PPVT-R/CELF/Evalo 2-6+PPVT-R): T1, T3

| Type | Format | Volume |
|-------------------------|----------|--------|
| video recording | .mp4 | 150 GB |
| paper scoring booklet | on paper | / |
| scan of scoring booklet | .pdf | 200 MB |

- Autism characteristics (ADOS-2) : T1, T3

| Type | Format | Volume (per time moment) |
|-------------------------|----------|--------------------------|
| video recording | .mp4 | 120 GB |
| paper scoring booklet | on paper | / |
| scan of scoring booklet | .pdf | 200 MB |

- Questionnaires important for this work package are: The Strengths and Difficulties Questionnaire (SDQ) and the Adaptive Behavior Assessment System (ABAS). Parents will fill these out directly in Redcap.

Data collection and creation:

Before the start of data collection

- an extended protocol will be written for each time point. This protocol contains detailed information on each measurement and the preferred order to perform the measurements. These protocols are written in step-by-step manner allowing easy follow-up/reproduction of the data collection for each work package.
- All PhD students and researchers will be trained to reliably administer all the experimental and clinical measures that are part of our protocol. This aspect is central to guarantee the feasibility of our study and to reduce site-specific biases.

During data collection

- In addition, each study aspect requiring to monitor the behavior of the child or parent for online/offline judgements is recorded.
- Researchers will meet twice a month during data collection discussing test administrations and irregularities. Also PhD students will rotate between labs to order to ensure consistency of assessments.
- Data will be managed with Redcap, a secure web-based application for building and managing online databases. The project will be on a secure server in KU Leuven, with a backup on a separate, secure location. A data dictionary can be exported, in which all variables and their descriptions are listed.
- Video and audio recordings will be shared with consortium members of the related work packages on Sharepoint, hosted by KU Leuven.

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:

Not applicable

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

This multi-center project will be approved by the local ethics committee of each center (ULB-Erasme Ethics Committee, Ghent University Hospital and KU Leuven's Ethics Committee) in accordance with the 1964 declaration of Helsinki and its later amendments. Moreover, we commit to respect the five 'person-oriented research ethics' guidelines for autism research: individualisation, acknowledgment of lived world, empowerment in decision-making, respect for holistic personhood, and focus on researcher-participant relationships. Parents of participants will be asked to sign an informed consent form in order to enroll their child in the study.

In this project, we will use non-invasive EEG and actigraphy techniques which involve no risk to participants.

During the project, paper data (e.g., informed consent, paper questionnaires) will be stored in a locked cupboard at each site separately, in an office that is locked when no-one is present. Identifiers will be kept separate from pseudonymised data. All digital data files will be stored on an internal secured network drive available only to the researchers.

When enrolled in the study, each participant will be assigned a code. The match between participant and code is kept in a password protected spreadsheet (IDcode.xlsx) on a protected server for each site separately. The PI and one assigned representative involved in data collection have access to this spread sheet for their site. The data at each site will be accessible only to those directly involved in the study. Each site will be able to grant access to researchers from other sites once the data has been completely pseudonymised and (for some tests) processed.

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

All personal data will be kept at each site on a password-secured spreadsheet that will be the only document linking the pseudonymised data to the identifiable data. Only researchers from said site that are involved in the project will have access to the spreadsheet.

Personal data:

- email
- birth date
- sex/gender
- job position & work place of parents
- Education level
- country, city, postal number
- age
- national insurance number (only needed for reimbursement)
- phone number
- home address
- first & surname
- native language
- Diagnostic data (autism)
- bank account parent(s) (only needed for reimbursement)

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.

- Yes

As this is a multisite study, a consortium agreement is in place, which has been signed by all three participating sites.

Further sites are working on a study-site agreement (including data processing agreement), which will need to be edited, approved and signed by all three participating sites.

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.

- Yes

The collected data will be owned by the research unit at each site, who collected the data. Data of the own site will be accessible, and also data of the work package one belongs to (also of the other sites).

Parents are informed on the potential reuse of the data for future research on typical and atypical (neuro)development. For future research, one should write a research proposal. All PIs have to approve the proposal before the relevant data can be shared.

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).

The documentation accompanying the data will be stored together with the data. It will include all documents related to ethics, i.e. the information and consent document and the complete study protocol. This documentation will contain all the details relating to data collection from recruitment plan to anonymization and storage.

Data will be managed with REDCap, a secure web-based application for building and managing online databases.

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.

- Yes

A data dictionary can be exported from Redcap, in which all variables and their descriptions are listed https://rdrr.io/cran/REDCapR/man/redcap_metadata_read.html).

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

Where will the data be stored?

Paper version questionnaires, booklets and informed consent

All forms will be kept per site. There is no need to transport paper forms across the three sites. All forms containing personal information (eg. informed consent, background questionnaire and diagnostic report) will be kept separately from the forms pseudonymised with participant number only, both in a different locked cupboard. The non-digital data files stored in a locked closet will only be accessible by the involved researchers and the (co-)promoters. The pseudonymised questionnaires are stored in a separate folder for each participant.

Digital personal information

All forms containing personal information (scanned informed consent, background questionnaire, diagnostic report, video and audio recordings), will be kept in a separate folder from the forms pseudonymised with participant number only, on a secured password-protected (network) drive. Only the researchers at the site involved in the project will have access to the unanonymized data.

Surveys will be filled out online by parents, directly in Redcap. In the exceptional case of paper questionnaires, these will be entered by researchers in Redcap. Only the site who saw a specific participant will be able to link the pseudocode of the participant to the identifying information, the other two sites will only have access to the pseudonymised data.

Digital pseudonymised data

The pseudonymised digital data files will be kept per site with access restricted to project team members to protect privacy. Within the folder of data collection, a subfolder per time moment is created, within each following subfolders are created: EEG (containing all data of the EEG), Audio (containing audio recordings), Clinical (containing scanned forms with the scans of scoring booklets of the IQ and language tests, ADOS, Comfor-2, imitation and joint attention tasks and doll house), and Video (containing all video recordings of the test sessions).

In addition, data will be managed with Redcap. The project will be on a secure server in KU Leuven, with a backup on a separate, secure location.

Audio and video material will be accessible by the researchers that are involved in the work package that needs these data, even if they are working in a different site. These materials will be shared in a pseudonymised way on the project's sharepoint. Data will be collected in folders where access is determined by the data manager (post-docs coordinating the study) and only granted after permission of the project's PIs, based on the work package content.

Data access will be limited in time. Only for the time needed to code the data, access will be granted. Before access to the video material is granted, the PhD student writes a proposal with their research questions and a list of the specific data needed to answer these research questions. Only after approval by the promoters of the study, access is granted.

How will the data be backed up?

The protected network drives of Ghent University, KU Leuven and ULB are backed up several times per day.

On Redcap and Sharepoint data is protected from data loss by regular backups.

Each site will make sure to keep manual back-ups on their protected external drive (also backed-up automatically).

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

At Ghent University, the capacity of each share is limited to 10 TB for security reasons. Additional shares can however be requested at all times.

Also on Sharepoint and Redcap there are no issues foreseen with regard to insufficient storage.

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

Only the researchers at each site involved in the project will have access to the unanonymized data. Raw unanonymized paper data (e.g., informed consents, personal information sheet) will be stored at each site in a locked closet. Only the researchers involved in data collection have access to forms containing personal information.

On all other paper files, such as assessments scoring sheets, only the pseudocode will be written. Raw electronic data (e.g., video/audio recordings) will be stored by each research unit at each site on a secured password-protected (network) drive in access-controlled folders with access restricted to project team members to protect privacy. These audio and video files will be named with the pseudocode, but it is inherent to the nature of this data (audio and video) that participants might be recognized. We ask parents for explicit consent to use these types of data. The videos and audio material will only be accessible by the researchers of the site where the child

participated in the study and by the researchers involved in the work package that uses the specific data (irrespective of site).

Processed pseudonymised data (e.g., standardized scores, video transcripts) will be stored at each site on a secured (network) drive. Only researchers involved in the study will have access to this drive.

In addition, data will be managed with Redcap, a secure web-based application for building and managing online databases. The Redcap project will be on a secure server in KU Leuven, with a backup on a separate, secure location. Different roles will be assigned to people, so that everyone has only access to a limited selection of data.

On Redcap and Sharepoint (where video and audio material will be stored), only researchers involved in the project will have access to the data of their own site (to be able to follow up data completion and for quality control) and to the data of their own work package.

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

There are no charges for the use of the shares.

Redcap and sharepoint are managed in KULeuven. For Redcap, a yearly fee of 80 euro for setup and maintaining is asked. This fee will be shared by the three consortium partners.

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...).

The internal secured network will remain available 5 years after the last publication to consortium members. Pseudonimized paper data will be scanned, stored on the same shares and the paper versions will be destroyed.

Raw data (such as the identifiable spreadsheet with personal and contact information, unprocessed EEG and actigraph signals, and unprocessed answered on questionnaires) will be preserved during that period as well, or until the results of the study are fully published.

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

After the end of the project, the data specified above will be kept at each site on a shared password-secured (network) drive. Physical data (paper versions) will be stored in the faculty archive for research material or in locked cupboards of the researchers involved in the study.

The data should be shareable to allow the other sites to keep access and if involved researchers leave the university after the end of the project. Data sharing between sites will happen in a pseudonymised way on Redcap and Sharepoint.

The data managers (post-docs coordinating the study) will still have access to these data.

After the aforementioned duration, all data related to this project will be destroyed.

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

There are no charges for the use of the shares.

Redcap and sharepoint are managed in KULeuven. For Redcap, a yearly fee of 80 euro for setup and maintaining is asked. This fee will be shared by the three consortium partners.

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, ...)

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

During the research project, data of the own site and data of the own work package(s) (irrespective of site) will be accessible for the researchers involved in the consortium. Access will be arranged by the data managers (post-docs coordinating the study), after approval by the project's PIs.

Participants are informed on the possible reuse of their data in future research (until 5 years after the last publication, then data is destroyed). If external researchers want access to the data, they should write a research proposal, that has to be accepted by all PIs. Only relevant data will be shared, not the whole data set will be accessible.

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

Video and audio material will not be shared outside of the consortium due to privacy concerns. This also applies to all information that allows for identification. If the data would be shared with researchers outside of the consortium, a second pseudonymisation will happen making it impossible to go back to the identifying information for the external researchers.

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

Initially, during data collection and processing, data will be on REDCap (surveys/questionnaires, scores of clinical and experimental tests, observation sheets, etc.) and Sharepoint (video and audio recordings).

After the core analyses on a specific topic are published, data will be stored in a data repository. The data repository is still to be determined.

When will the data be made available?

Initially, during data collection and processing, data will be on REDCap (surveys/questionnaires, scores of clinical and experimental tests, observation sheets, etc.) and Sharepoint (video and audio recordings) data will be available to researchers involved in the consortium.

Only after publication of the core analyses, data can be made available for external researchers, until 5 years after the last publication, as data will be destroyed then.

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

None. Data is shared only after approval by the PIs of the consortium, based on a research proposal that was submitted by the researcher interested in data access.

Pseudonymized data will only be shared outside of the consortium after a second pseudonymisation.

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?

Redcap and sharepoint are managed in KULeuven. For Redcap, a yearly fee of 80 euro for setup and maintaining is asked.

In the future, the data will be stored on a data repository, free of charge. So no costs are expected here.

6. Responsibilities

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

Postdoctoral researchers (KUL Lotte van Esch; UGent Ellen Demurie; ULB Pauline Maes); PhD students and research assistants (UGent Anouk Matthys, Hanna Van de Vyver, Nele Bogaert, Marlies Camerlinck; KUL Ines Brys, Klaartje Vertongen, newly hired research assistant; ULB Clara Rapp, Marine Petit, Federica Beccaria, Lena Petrocelli)

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

Postdoctoral researchers (KUL Lotte van Esch; UGent Ellen Demurie; ULB Pauline Maes); PhD students and research assistants (UGent Anouk Matthys, Hanna Van de Vyver, Nele Bogaert, Marlies Camerlinck; KUL Ines Brys, Klaartje Vertongen, newly hired research assistant; ULB Clara Rapp, Marine Petit, Federica Beccaria, Lena Petrocelli)

Who will manage data preservation and sharing?

Principal investigators (KUL Ilse Noens; UGent Herbert Roeyers; ULB Mikhail Kissine) and respective postdoctoral researchers (KUL Lotte van Esch; UGent Ellen Demurie; ULB Pauline Maes)

Who will update and implement this DMP?

Principal investigators (KUL Ilse Noens; UGent Herbert Roeyers; ULB Mikhail Kissine) and respective postdoctoral researchers (KUL Lotte van Esch; UGent Ellen Demurie; ULB Pauline Maes)

Belgian Language in Autism Study

DPIA

DPIA

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

- Yes