



# Data access and publication guidelines

## YOUth

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YOUth is an initiative of Utrecht University and University Medical Center Utrecht, and is funded through the Gravitation program of the Dutch Ministry of Education, Culture, and Science and the Netherlands Organisation for Scientific Research for the Consortium Individual Development (CID) (NWO grant number 024.001.003).

This Data Access Protocol is written in consultation with the **YOUth Executive Board**, the **YOUth Management Team**, the **YOUth Data Access Committee**, the **CID work package 1**, **UU and UMCU legal departments**, and the **University Library Utrecht**.

**DISCLAIMER:** this is a living document that will be amended and updated regularly. Consequently, no rights can be derived from the text of this publication.

[www.uu.nl/youthcohort](http://www.uu.nl/youthcohort)

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# 1 General

The YOUth cohort is part of the Consortium on Individual Development (CID). CID examines how the environment (family characteristics, parents and siblings, peers, and broader societal influences including media) and child characteristics (genetic makeup, temperament, and pre- and peri-natal factors) affect the development of social competence and behavioral control. CID was one of the six teams to receive a grant from the Dutch Science Foundation (NWO, grant number 024.001.003) to collaborate over a period of ten years. The grant is part of the Gravitation Program by the Ministry of Education, Culture and Science (OCW) to fund highly ambitious research programs that have the potential to bring about international breakthroughs. Since May 2013, CID unites top-tier researchers from several disciplines, each with unique and relevant expertise in development research, working at seven Dutch universities and University Medical Centers. YOUth relates to one of the four work packages of CID (WP1). At Utrecht University, CID is embedded in Dynamics of Youth (DoY), one of Utrecht University's four strategic themes, and in Child Health, one of the research themes of the University Medical Center Utrecht

YOUth is a large-scale longitudinal cohort study following children from the city of Utrecht and its surrounding areas in their development from pregnancy until early adulthood. The YOUth cohort focuses on neurocognitive development involved in two core characteristics of behavioral development: social competence and behavioral control. YOUth includes children from the general population to cover the whole range of variation in behavioral development, ranging from uncomplicated development, through problem behavior, to psychiatric disorders. To understand why some children develop problematic behavior, and others show resilience, YOUth measures a broad range of biological, child-related and environmental determinants.

YOUth conducts repeated measurements at regular intervals (i.e. 'waves'). Specifically, the study has two inclusion moments: YOUth Baby & Child and YOUth Child & Adolescent. The first group, YOUth Baby & Child, includes 3000 pregnant women at 20 weeks of pregnancy, and their partners. Recruitment has started in July 2015 and is still ongoing. The children that are being born from these pregnancies visit our Child Research Center at several moments during their lives and are followed for at least 6 years. The second group, YOUth Child & Adolescent, includes 1300 children aged 8, 9 or 10 and their parents. These children visit our Child Research Center every three years, for at least three times. YOUth applies a flexible longitudinal design to the cohorts, meaning that children will be measured at broader age ranges (3-year age ranges) at each wave. The main benefit of the flexible age design is that it will provide more detailed information on the neurodevelopmental curves over time.

An extensive data set is generated, including 3D-ultrasound sweeps of the fetal brain, eye tracking, EEG, (f)MRI, computer tasks, cognitive measurements and parent-child observations. We also collect a broad range of questionnaires on behavior, personality, health, lifestyle, parenting, child development, use of (social) media and more. Finally, (umbilical) blood samples, buccal swabs, saliva and hair samples are collected at each visit, and stored in the UMC Utrecht Biobank. A complete overview of the data collection can be found [here]. Our catalogue with item-level descriptions is available upon request.

In YOUth, Open Science plays an important role. YOUth encourages and facilitates extensive and appropriate use of its data by bona fide research organizations and bona fide researchers. To

enable this, YOUth goes to great lengths to produce high quality, FAIR (Findable, Accessible, Interoperable and Reusable), and thereby sustainable data while safeguarding the privacy of participants. YOUth also strives to increase openness, integrity, and reproducibility of the science performed with its data. YOUth therefore envisions that the process, content, and outcomes of research performed with its data are openly accessible by default. YOUth also requires researchers to pre-register their study and publication plans prior to analysis and publication on the YOUth Registry of the Open Science Framework (<http://osf.io/registries/youthstudy>).

The objective of this document is to outline in detail the conditions, procedures and processes involved in accessing YOUth data and in publishing with YOUth data. The process for accessing data is the same for all, regardless of research area, institution, location or funding source, provided the proposed research is in the public interest and is **not** being carried out for personal or commercial gain.

## 2 Definitions

Bona fide: YOUth employs the [MRC definition](#) of bona fide; please contact us if you are in any doubt as to whether you fit this definition.

Bona fide research can be considered to be as follows:

- An intention to generate new knowledge and understanding using rigorous scientific methods (including discovery research, development and validation of methodology and technology, validating and challenging previous findings, and pilot research).
- An intention to publish the research findings and share the derived data in the scientific community, without restrictions and with minimal delay, for wider scientific and eventual public benefit.
- The intended activities are not inconsistent with legal and ethical requirements or widely recognized good research practice.

In practical terms, a research project or proposal that has been approved by a recognized funder should normally be considered to be “bona fide”.

A bona fide research organization is one that has the capability to lead or participate in high quality, ethical research. It will have a public commitment to adhere to recognized research and information governance good practice. (It is not a requirement that such research is the primary business of that organization, or that all the research undertaken by that organization is published. Nor is it a requirement that the organization be publicly funded.)

A bona fide researcher is a person with

- the professional expertise and experience to conduct bona fide research and
- a formal relationship with a bona fide research organization that requires compliance with appropriate research governance and management systems.

CID:	Consortium on Individual Development.
Cohort profile paper:	The paper describing the design of the YOUth cohort: <a href="https://www.sciencedirect.com/science/article/pii/S1878929320301183?via%3Dihub">https://www.sciencedirect.com/science/article/pii/S1878929320301183?via%3Dihub</a>
Data Manager:	The person responsible for the intake, quality control, storage and distribution of the YOUth data. The Data Manager also evaluates data requests in terms of practical feasibility and privacy concerns.
Data Access Committee:	The Data Access Committee (DAC) evaluates data requests. The Data Access Committee consists of the project manager, the data manager, the members of CID WP1, and the domain controllers.
Data lock:	A subset of the data that is locked on a specific date and can then be handed out to researchers for data analysis.
Data package:	Well-structured folder consisting of (raw) data, syntax file(s), Readme.txt file (explaining methods and structure of the data package), and a version of the paper in word and pdf. A researcher is responsible for securing and archiving its data package together with a metadata scheme in the Yoda repository.
Data set:	A collection of data. YOUth has data sets for each wave (single experiments and questionnaires).
Domain controller:	For each research domain, one researcher is ultimately responsible for its data quality, training of research assistants, etc. Domain controllers invest heavily in the YOUth data collection in their domain, and are experts in the relevant research techniques and/or subject areas. A list of domain controllers is available on the <a href="#">YOUth researcher's website</a> .
Executive Board:	The people responsible for the executive decisions of YOUth. The Executive Board consists of the Scientific Director / Cohort Representative, the Leader of CID work package 1, the Executive Director, and the Project Manager.
FAIR data principles:	Findable, Accessible, Interoperable and Reusable data.  <i>Findable</i> : metadata and data should be easy to find for both humans and computers. Machine-readable metadata are essential for automatic discovery of datasets and services.

- Data are described with rich metadata.
- (Meta)data are assigned a globally unique and persistent identifier (for example a DOI).
- (Meta)data are registered or indexed in a searchable resource.

*Accessible:* it should be possible for humans and machines to gain access to your data, under specific conditions or restrictions where appropriate. FAIR does not necessarily mean that data need to be open! In cases where the data cannot be made openly accessible, it is still possible to make the metadata publicly available.

- The repository used to share data assigns persistent identifiers by which data can be retrieved.
- The access procedure includes authentication and authorization steps, if necessary.
- Metadata are accessible, wherever possible, even if the data are not.

*Interoperable:* to speed up discovery and uncover new insights, research data should be easily combined with other datasets, applications and workflows by humans as well as computer systems.

- When possible, well-known and preferably open formats and software are used.
- Relevant standards for metadata are used.
- Community agreed schemas, controlled vocabularies, keywords, thesauri or ontologies are used where possible.

*Reusable:* Research data should be ready for future research and future processing, making it self-evident that findings can be replicated, and that new research effectively builds on already acquired, previous results.

- The data are well-documented to support proper data interpretation.
- The data have a clear and accessible data usage license, so others know what kinds of reuse are permitted.
- The data have provenance information to make clear how, why and by whom the data have been created and processed.
- The data (and metadata) meet relevant domain standards.

**Management Team:**

The people responsible for the daily management of YOUth. The Management Team consists of the Executive Board (Scientific Director / Cohort Representative, the Leader of CID work package 1, the Executive Director, and the Project Manager), and the Logistics Manager, the FAIR data IT project manager, and the Senior Communications Advisor.

Preregistration	<p>YOUth employs the definition of preregistration of the Center for Open Science (<a href="https://www.cos.io/initiatives/prereg">https://www.cos.io/initiatives/prereg</a>): specifying your research plan in advance of your study and submitting it to a registry. Preregistration separates hypothesis-generating (exploratory) from hypothesis-testing (confirmatory) research. Both are important. But the same data cannot be used to generate and test a hypothesis, which can happen unintentionally and reduce the credibility of your results. Addressing this problem through planning improves the quality and transparency of your research. This helps you clearly report your study and helps others who may wish to build on it.</p> <p>Preregistration of studies using YOUth data occurs on the <a href="http://osf.io/registries/youthstudy">YOUth Registry</a> of the Open Science Framework (<a href="http://osf.io/registries/youthstudy">http://osf.io/registries/youthstudy</a>), using the YOUth preregistration templates.</p>
Publication:	An article, abstract or presentation at professional meetings, summarizing with the purpose to disseminate research findings to the scientific community.
Research domain:	A combination of measurements with a similar experiment type (e.g., EEG, questionnaires) that can span multiple waves.
Research question:	A well-defined and specific question that includes determinant, outcome, and domain (the group of people that you want to generalize the results of the study to). A research question should be answerable in one publication.
Subset:	A set of data that is still incomplete and does not contain all participants of a specific wave.
Verification:	(An attempt) to exactly reproduce results of analyses conducted by others, using the same analysis script and exact same data set.
Wave:	All pregnant women and children visit the center at regular time intervals. These visits are called “waves” and for the participants “Rondom xx”, where xx stands for the average age of the children in that specific wave.
Yoda:	A service that provides Utrecht University researchers and their partners with a workspace and an archive that enables them to collaborate, deposit, publish, and securely preserve research data (long term). YOUth uses Yoda for various purposes including data access and archiving of data packages. For more information, please visit <a href="https://yoda.uu.nl">https://yoda.uu.nl</a> .
YOUth:	Youth Of Utrecht cohort including children and their parents living in the city of Utrecht and its surrounding areas.

### 3 Data ownership

**Data ownership** lies with UU and the UMCU, as described in the Consortium Agreement of CID and the Additional Agreement on Data (both available upon request from the Project Manager). Data ownership always remains with these parties and cannot be transferred to other parties. User rights are limited to (non-exclusive) access to the data set specified in the data request and to use of this data set as specified in the data request. Any data generated through an approved project must be returned to YOUth to encourage ongoing use by the research community.

### 4 Conditions of data use

- YOUth can only grant access to researchers within the European Union, where the General Data Protection Act applies.
- YOUth can only grant access for bona fide research, to bona fide researchers who are employed at a bona fide research organization (see definition above). (PhD-) students at a bona fide research organization who are not employed by that organization can only be granted access under responsibility of their supervisor who is employed at that organization, through a request submitted by their supervisor.
- Proposed projects must fall within framework of YOUth and within the limits specified in the informed consent provided by the participants of YOUth.
- YOUth grants data access for dedicated research questions only. The research question should be precisely specified in the data request form. Data can only be used for exploratory analyses if reported as such in the output of the research specified in an accepted data request.
- YOUth only grants access to requested data after approval of the data request by the Data Access Committee, a verified preregistration of the approved request on the public [YOUth Registry](http://osf.io/registries/youthstudy) of the Open Science Framework (<http://osf.io/registries/youthstudy>), and obtaining mutual signatures of the Data Transfer Agreement.
- YOUth only shares demographic variables that are essential to answering the proposed research questions, not for sample descriptions. Sample descriptions including specific demographic variables can be provided by the Data Manager upon request.
- Access to biological materials can only be granted after additional approval from the “*Toetsingscommissie Biobanken*” (TCBio) of the UMC Utrecht. The standard access protocol of the TCBio needs to be followed (<https://tcbio.umcutrecht.nl>) or contact TCBio@umcutrecht.nl
- Output of the research specified in an accepted data request should in principle be limited to a single paper in a peer-reviewed journal, a report, thesis, or other form of scientific output. With this policy, YOUth aims to prevent piecemeal publication. This is defined as the unnecessary submission of findings from the same study in piece by piece fashion, rather than as an integrated single report (APA, 2010). The planned output should therefore be specified in the data request form and the accompanying preregistration. Submissions of conference

abstracts do not need to be specified in the proposal and do not follow the same rules as other publications, unless this is the primary mode of publication in your research field (e.g. computer science).

- YOUth acknowledges the importance of collaboration with other (cohort) studies and stimulates collaboration in (inter)national consortia. However, data access for use in (collaboration in) consortia cannot be granted to an individual researcher. When a researcher wishes to collaborate in a larger consortium with YOUth data, they can contact the YOUth Data Access Committee through the Project Manager.
- Requests for additional / joint data collection follow a separate procedure: Please see the YOUth add-on studies protocol on the website (*url following soon*).

## 5 Data request procedure

An overview of available data and a prospectus containing detailed information on all measurements is provided on the [YOUth Researcher's website](#).

When a researcher wishes to access YOUth data, they need to submit an online data request form through the [YOUth online data request system](#). The data request form requires a detailed description of the proposed study. For a preview of the request form please see [here](#).

After receipt of a data request, the following evaluation procedure starts:

- 1) The Project Manager evaluates
  - a. Whether the data request is complete
  - b. Whether the applicant(s) and their institution(s) fit the definition of 'bona fide'
  - c. Whether the proposal falls within the framework of YOUth (*brain and behavioral development of babies and children, with a focus on social competence and behavioral control*) and within the limits of the Informed Consent provided by participants (*research on development of behavior, deviations in behavior, and brain development*)
- 2) The Data Manager assesses the potential risk of disclosing identifiable information with the requested data.
- 3) The members of CID WP1 and de domain controllers a) evaluate whether the proposed project conflicts with their ongoing or future projects and b) indicate whether they wish to become involved in the proposed project and/or resulting publication.
- 4) When a data request is approved, the applicant is required to publicly preregister their data request in the [YOUth Registry](#) of the Open Science Framework (<http://osf.io/registries/youthstudy>). The preregistration form in the YOUth Registry consists of the same questions as the data request form, allowing copying and pasting from the approved data request form. The approved data request also needs to be uploaded to

the YOUth Registry. The Project Manager verifies the preregistration in the YOUth Registry and notifies the Data Manager.

- 5) The data manager provides a Data Transfer Agreement (DTA) which has to be filled out and signed by the applicant(s) and by a representative of the applicant's institution<sup>1</sup>. There are 4 different DTA's available; the type of DTA the applicant will receive depends on at which type of institution the applicant is employed.
- 6) When the Data Manager has received the signed DTA they will make the requested data available through a secure data transfer process.

N.B. If the data request involves the use of biological samples, the applicant needs to apply for additional approval from the "toetsingscommissie Biobanken" (TCBio) of the UMCU. This approval can only be obtained after approval of the data request by the YOUth Data Access Committee and should thus occur between steps 3 and 4 in the procedure outlined above. The applicant needs to fill out the application form of the TCBio, which can be found on the TCBio website (<https://tcbio.umcutrecht.nl>). Materials that need to be included in the application for the TCBio (informed consent forms, brochures, etc.) can be provided by our METC policy officer.

- 7) An application for an amendment to the original data request needs to be completed and evaluated **through the same online procedure** as the original data request in any of the following circumstances:
  - The applicant wishes to conduct other analyses than those that were specified in the original data request and the accompanying preregistration
  - The applicant requires additional data than those that were specified in the original data request and the accompanying preregistration

N.B. An approved amendment to a data request must be followed by an update of the preregistration, while the original preregistration remains visible and unchanged.

- 8) An application for an amendment to the original data request needs to be submitted **through e-mail to the Project Manager** in any of the following circumstances:
  - The applicant needs to change the end date
  - Researchers other than those who were specified in the original data request and the accompanying preregistration have been added to the research group
  - The main applicant changes institution

N.B. An approved amendment to a data request must be followed by an update of the preregistration, while the original preregistration remains visible and unchanged.

- 9) The researcher is responsible for securing and archiving the data package in Yoda prior to publication of the results of the research project as prescribed in the Data Transfer Agreement.

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<sup>1</sup> only applicable for researchers from a different legal entity than the UU

- 10) The researcher is responsible for securely destroying data and/or derivatives from the workplace and/or any data carriers, as prescribed in the Data Transfer Agreement.

## 6 Data access for verification purposes

Researchers who publish with YOUth data are responsible for the replicability and verifiability of their research. When journal editors, reviewers, or other researchers wish to obtain access to the data to verify results, the original applicant can submit an online data request for verification linked to their original request. In this data request for verification, the contact details of the person requesting the data for verification should be provided.

The evaluation of the data request for verification will follow the same procedure as an original data request. When the data request for verification is approved, a representative of the institution of the person requesting the data for verification needs to sign a specific Data Transfer Agreement. This Data Transfer Agreement states that the data can only be used for verification purposes and that publication about anything other than the results of the verification attempt is prohibited.

## 7 Publication guidelines

### Obligatory:

1. Relevant Domain Controllers, PI's and other researchers who have been involved in collecting the data, should be invited to co-author the manuscript. As part of the online data request procedure these researchers can indicate their wish to be involved and they will be connected to the researchers requesting the data after approval of the request.
2. The [YOUth Cohort profile paper](#) should be cited in the manuscript as Onland-Moret, N. C., Buizer-Voskamp, J. E., Albers, M. E., Brouwer, R. M., Buimer, E. E., Hessels, R. S., ... & Kemner, C. (2020). The YOUth study: Rationale, design, and study procedures. *Developmental cognitive neuroscience*, 46, 100868. <https://doi.org/10.1016/j.dcn.2020.100868>
3. The manuscript should include the keyword **"YOUth Cohort Study"**
4. The manuscript should include the following statement in the Acknowledgements section: *"YOUth is funded through the Gravitation program of the Dutch Ministry of Education, Culture, and Science and the Netherlands Organization for Scientific Research (NWO grant number 024.001.003). A complete listing of the study investigators and study management can be found at <https://www.uu.nl/en/research/youth-cohort-study/about-us/who-is-involved>. YOUth investigators and management designed and implemented the study and/or provided data but did not necessarily participate in the analysis or writing of this report. This manuscript reflects the views of the authors and may not reflect the opinions or views of the YOUth study investigators or YOUth management."*

5. The researcher is required to let the Management Team know when the paper is accepted for publication through the Secretary of the Scientific Director ([I.Bleeker@uu.nl](mailto:I.Bleeker@uu.nl)) and the Project Manager ([c.i.s.veldkamp@uu.nl](mailto:c.i.s.veldkamp@uu.nl)).
6. The researcher is required to send a copy of the final submitted paper and any revised versions, including publication details, to the Secretary of the Scientific Director ([I.Bleeker@uu.nl](mailto:I.Bleeker@uu.nl)) and the Project Manager ([c.i.s.veldkamp@uu.nl](mailto:c.i.s.veldkamp@uu.nl)).
7. Researchers who use YOUth communication materials are required to use the following **YOUth logo**



And this **footer** on flyers, posters, letters, etc.:

YOUth is an initiative of:



Utrecht University



UMC Utrecht

Encouraged:

8. Where possible, Early Stage Researchers, in particular post-docs and PhD students, shall be given priority as Lead Authors. For authorship credits YOUth strongly encourages researchers to follow the Vancouver protocol<sup>2</sup>.
9. YOUth fully supports the (Dutch) National Plan Open Science ([www.openscience.nl](http://www.openscience.nl)). Therefore, we encourage researchers to publish their papers in open access journals. Authors should be aware of the possibility to use Creative Commons licenses.
10. In case of a press release or interview, YOUth encourages researchers affiliated with YOUth to contact the YOUth Communication team who can assist with the media coverage.

**The YOUth Management Team reserves the right to withhold a manuscript from submission or publication in case of violation of the Data Access Protocol and/or of the Publication Guidelines.** A pre-publication checklist for publishing papers with YOUth data is provided in the appendix.

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<sup>2</sup> Ann Intern Med. 1997;126:36-47.

## 8 Disclaimers

- It is the applicant's responsibility to determine whether any other researchers are addressing or have addressed the same research questions. An overview of approved data requests can be found at <https://www.uu.nl/en/research/youth-cohort-study/data-access/approved-data-requests>) and the YOUth Registry (<http://osf.io/registries/youthstudy>); an overview of publications based on YOUth data can be found at <https://www.uu.nl/en/research/youth-cohort-study/youth-publications>.
- In case of conflicting requests, Domain Controllers or other individuals or teams with a more prominent role in the development, inclusion, and/or continuation of YOUth are given priority for analysis of the same dataset.
- If a member of the Data Access Committee notices overlap in research questions with approved data requests during the evaluation process, they will inform the Project Manager, who will contact the researchers already working on the overlapping research question(s) and connect the researchers involved.
- Data that have not yet been fully pseudonomized cannot be shared outside Utrecht University and the University Medical Hospital Utrecht, or outside the Consortium on Individual Development. Currently, these data include video and ultrasound images.
- All projects requesting YOUth data should be appropriately funded. When funding is contingent on the data request being approved, it is the applicant's responsibility to submit a data request in time.
- The speed of the data request procedure is dependent on YOUth's capacity. YOUth therefore cannot make any promises about when the applicant will receive a definitive answer to a data request.
- YOUth aims to be as FAIR and open as possible, but the security and privacy of our participants and data remains our highest priority. YOUth therefore reserves the right not share any data that may involve potential security and/or privacy issues.

## 9 Appendix

### Pre-publication checklist YOUth (version 3.0, June 27, 2022)

		Yes	No	N/A
	<b>Pre-submission:</b>			
1.	I have invited all researchers who were listed as eligible for co-authorship in the data access request procedure to co-author the manuscript			
2.	I have cited the YOUth Cohort profile paper			
3.	I have included "YOUth Cohort Study" as keyword			
4.	I have included the standard YOUth acknowledgements statement.			
5.	When applicable: I have used the appropriate logo and/or footer regarding YOUth communication materials			
	<b>Post-submission:</b>			
7.	I have sent a copy of the final submitted paper and any revised versions.			
8.	I notified the Management Team that the paper is accepted for publication and have sent the final publication as an attachment and/or url			