

# **Developing Human Connectome Project (dHCP)**

# Guidelines for downloading data from the NDA

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- 1. Before you start
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#### Before you start you will need:

- 1. NDA user account <u>https://nda.nih.gov/nda/creating-an-nda-account.html</u>
- 2. Data access permission https://nda.nih.gov/nda/access-data-info.html
- 3. Download the 'Download Manager Tool' <u>https://nda.nih.gov/nda/nda-tools.html#download-manager</u> (see FAQ for username and password)

#### Downloading data:

- 1. Clink on the link <u>https://nda.nih.gov/edit\_collection.html?id=3955</u>
- 2. Click "Add to cart"

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4. Check that all options are selected in the left table (collections by Permission Group). Select the modality in the right table (Data Structure by Category). The list below describes the neonatal data available in each modality.

To access packages you have created, open the Data Packages page from your user profile.			
Researchers who share data through NDA, or who conduct a secondary analysis on data shared through NDA, are expect release, or publication directly to the underlying subject-level records for the data defined. Automatically, the NDA Stud- (DDI), which is expected to be referenced in the publication as a presistent link to the supporting dataset	2. Select modality		
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Developing Human Connectome Project (dHCP)	Adverse Events		
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(GHCP)	Autism Spectrum Disorders		
I 3955] Developing Human Connectome Project (dHCP)	Quantitative Checklist for Autism in Toddlers (617 of 617 subjects available)		
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### Adverse Events



• **NICU Episode Summary:** Clinical information for babies that stayed in the NICU. Data in file nicu101.

# Autism Spectrum Disorders

**Quantitative Checklist for Autism in Toddlers:** Q-CHAT scores (18 month follow-up) Scores in file qucht01.

## **Checklist**

**Quantitative Checklist for Autism in Toddlers:** Q-CHAT scores (18 month follow-up) Scores in file qucht01.

# DTI, MRI, fMRI

**Image:** Native data and motion corrected images including anatomical, dMRI and fMRI and ancillary files related to the original examinations. The full cohort is arranged across 7 folders (DTIMRIFMRI/image03/rel3\_derivatives/rel3\_rawdata\_vol1-7), each with multiple sub-folders for individual subjects. All data for each subject is collected together in these individual subject folders.

# **Demographics**

- **NICU Episode Summary:** Clinical information for babies that stayed in the NICU. Data in file nicu101.
- **Participant Enrollment:** Parental clinical, demographic and socio-economic information. Data in file cpenr01.

# **Depression**

- Edinburgh Postnatal Depression Scale: EPDS scores. Data in file epds01.

# **Diagnostic**

- **NICU Episode Summary:** Clinical information for babies that stayed in the NICU. Data in file nicu101.

# Evaluated Data

**Processed MRI Data.** Analysed metadata for each modality (anatomical, diffusion, functional), including brain segmentations and cortical surfaces. The data are in folder fmriresults01/rel3\_derivatives. They are split in anatomical (rel\_dhcp\_anat\_pipeline), diffusion MRI (rel3\_dhcp\_dmri\_eddy\_pipeline and rel3\_dhcp\_dmri\_shard\_pipeline), functional MRI (rel3\_dhcp\_fmri\_pipeline). Within each modality the data are organised in folders by participant.

## Eye Tracking

**Eye Tracking Subject-Experiment:** native and processed eye-tracking data. Data are in folder et\_subject\_experiment01. The data are organised in folders by participant. Documentation on eye-tracking task, acquisition and analysis are in folder

et\_subject\_experiment01/experiments/experiment\_2018/block\_1/Block\_Design\_File/

## **Family**

- **Fetal Scan Information:** Information about the fetal scan, including the gestational age on the day of the scan. Data are in file fsi01.
- **Neonatal Scan Information:** Information about the neonatal scan, including age at scan, age at birth and sex. Data are in file nnsi01.
- **Parent's Questionnaire Mother's and Father's Questionnaire Combined:** 18 month time point. Parenting Scale scores and parental demographics. Data are in file pqmf01.

## <u>Health</u>

• **Neonatal Scan Information:** Information about the neonatal scan, including the gestational age at birth, the baby's age on the day of the scan and the baby's sex. Data are in file nnsi01.

## Med History

**Fetal Scan Information:** Information about the fetal scan, including the gestational age on the day of the scan. Data are in file fsi01.



#### **Omics**

- **Genomics Sample:** Genomic data can be found in folder genomics\_sample03/Users/nickharper/cdb/dhcp\_plink\_files. Methylation data can be found in folder
- genomics\_sample03/Users/nickharper/cdb/Methylation.

### Parenting

- **Late Pregnancy and Birth**: clinical information about later stages of pregnancy and birth. Data are in file lpb01.
- Parent's Questionnaire Mother's and Father's Questionnaire Combined: 18 month

timepoint. Parenting Scale scores and parental demographics. Data are in file pqmf01.

# Phys Exam

Neonatal Scan Information: Information about the neonatal scan, including the gestational

age at birth, the baby's age on the day of the scan and the baby's sex. Data are in file nnsi01. **Questionnaire** 

- **Bayley-III Scales of Infant Development:** 18 month timepoint, Bayley-III scores. Data are in file bsid\_iii01.
- **Child Behavior Checklist (CBCL) 1-5:** 18 month timepoint, CBCL scores. Data are in file cbcl1\_501.
- **Early Childhood Behavior Questionnaire:** 18 month timepoint, ECBQ scores. Data are in file ecbq01.
- **Parent's Questionnaire Mother's and Father's Questionnaire Combined:** 18 month timepoint. Parenting Scale scores and parental demographics. Data are in file pqmf01.
- Stimulating Parent Scale: 18 month timepoint, SPS scores. Data are in file stps01.

### **Resolve Identifiers**

- **Genomics Subject:** NICK description. Data are in file genomics\_subject02.
- **Research Subject:** List of every participant in study. Data are in file ndar\_subject01
- 5. After selecting the modality (e.g. eye-tracking), click "Create Data Package".

	Find All Subject Data Return 🧧 Create Data Package 🌙 Add Data to Study
Collections by Permission Group	Data Structure by Category
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Developing Human Connectome Project (dHCP)	Adverse Events
Login for access	NICU Episode Summary (0 of 190 subjects available)
Investigators: David Edwards, Jo Hainal, Daniel Rueckert, Stephen Smith	Autism Spectrum Disorders
Description: Few advances in neuroscience could have as much impact as a precise global description of	
human brain connectivity (connectome) and its variability. Understanding this connectome in detail will provide insights into fundamental neural processes and intractable neuropsychiatric diseases. Currently, the	Quantitative Checklist for Autism in Teddlers (0 of 617 subjects available)
connectome of the mature adult brain is in progress. The Developing Human Connectome Project (dHCP), led	
progress by creating the first 4-dimensional connectome of early life. Our goal is to make major scientific human brain connectivity from 20 to 44 weeks post-conceptional age, which will link together imaging.	Image (0 of 782 subjects available)
clinical, behavioural, and genetic information. This unique setting, with imaging and collateral data in an	Demographics
expandable open-source informatics structure, will permit wide use by the scientific community, and to undertake pioneer studies into normal and abnormal development by studying well-phenotyped and	NICU Episode Summary (0 of 190 subjects available)
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6. Create a name for your selected data package and select option "include associated files". Click "Create Data Package".

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NOTE: This may not represent all available data for these subjects - click "Find All	Subject Data" to return all dat	a for these subjects.			
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Investigators: David Edwards, Jo Hainal, Daniel Rueckert, Stephen Smith	Create Data Package	× or A	utism in Toddlers (0	of 617 subjects available)	
Description: Few advances in neuroscience could have as much impact as a p human brain connectivity (connection-) and dis variability. Understanding this con- insights into fundamental neural processes and intractable neuropsychiatric das connections of the mature adult train is in progress. The Developing Human Co- by King's College London, Timperial College London and Colord University, aims progress by creating the first 4-dimensional connections of a party ( <i>Bc</i> . Our goal). behavioural, and genetic information. This aimque setting, with imaging and col- open-source informatics structure, will permit wide use by the coefficient studies into normal and absormal development by studying well-phenotyped as with specific genetics and environmental risks that could lead to Austic Spectre	Please name your data package a below. Your data package name n cannot include special characters. Package Name Include Documentation * Include associated data file Exclude null columns * You MUST select this option if data files (c.a. MRL genomic, ran data files (c.a. MRL genomic, ran	Ind select additional options nust start with a letter and EVETRACKING EVETRAC	utism in Toddiers (0	ef 617 subjects available) L. Name your dat option	<mark>a package</mark>
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7. Popup window: Click 'here' to view the progress of the data package creation or 'ok' to stay on the package creation page.

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Dataset - 52160 (0 subjects) - Shared pipeline_BIDS_files, 009100	Neonatal Scan Information	on (0 of 805 subjects	available)	
Dataset - 52161 (0 subjects) - Shared pipeline BIDS files, 009200	Med History			

8. Open the 'Download Manager tool' and log in. The data packages are shown on the left. Navigate through the folders. The tool allows you to visualise the data available for download. Individual files can then be downloaded locally.



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9. Check your download directory. Go to 'Setting' and 'choose your download directory'.

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### Brain Imaging Data Structure (BIDS)

Data naming has followed the BIDS convention. Details can be found here <u>https://bids-standard.github.io/bids-starter-kit/</u>

#### **Frequently asked questions**



1. Where can I find information about the study and the data available?

You can visit the study website <u>http://www.developingconnectome.org/project/</u>. The neonatal data publication can be found <u>https://pubmed.ncbi.nlm.nih.gov/35677357/</u>.

2. Where can I find the age at scan for my analysis?

For neonatal data analysis, age at scan and age at birth can be found in 'Neonatal scan information' (file nnsi01). Look at variables 'NSCAN\_GA\_AT\_BIRTH\_WEEKS' and 'NSCAN\_GA\_AT\_SCAN\_WEEKS'. For fetal data analysis, gestational age at scan can be found in 'Fetal scan information (file fsi01). Look at variable 'FSCAN\_GA\_AT\_SCAN'.

3. Where can I find information about the parents?

Parental clinical, demographic and socio-economic information can be found in 'Participant enrollment' (file cpenr01).

- 4. Where can I find the BIDS naming descriptions? Details can be found here <u>https://bids-standard.github.io/bids-starter-kit/</u>
- 5. Where can I find my username and password for the Download Manager? Log into your NDA account and go to your profile page https://nda.nih.gov/user/dashboard/profile.html

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