



# Developing Human Connectome Project (dHCP)

## Guidelines for downloading data from the NDA

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### Before you start you will need:

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

### Downloading data:

1. Click on the link [https://nda.nih.gov/edit\\_collection.html?id=3955](https://nda.nih.gov/edit_collection.html?id=3955)
2. Click "Add to cart"

The screenshot shows the NDA website interface for the 'Developing Human Connectome Project (dHCP) #3955'. The page includes a navigation bar with links like 'Contribute Data', 'Get Data', and 'Data Dictionary'. Below the navigation bar, there are tabs for 'General', 'Experiments (4)', 'Shared Data', 'Publications (0)', 'Data Expected (18)', and 'Associated Studies (0)'. The 'General' tab is selected, displaying the following information:

- Collection Title:** Developing Human Connectome Project (dHCP)
- Collection Investigators:** David Edwards, Jo Hajnal, Daniel Rueckert, Stephen Smith
- Collection 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 connectome of the mature adult brain is in progress. The Developing Human Connectome Project (dHCP), led by King's College London, Imperial College London and Oxford University, aims to make major scientific progress by creating the first 4-dimensional connectome of early life. Our goal is to create a dynamic map of human brain connectivity from 20 to 44 weeks post-conceptual age, which will link together imaging, clinical, behavioural, and genetic information. This unique setting, with imaging and collateral data in an 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 genotyped group of infants with specific genetic and environmental risks that could lead to Autistic Spectrum Disorder or Cerebral Palsy.
- Data Repository:** Connectome Coordination Facility
- Permission Group:**
- Collection Creation Date:** 07/02/2021
- Collection Phase:** Enrolling
- Blinded Clinical Trial:** No
- Subjects Shared:** 874
- Funding Sources:**

On the right side of the page, there is a Venn diagram showing the overlap of data types: Imaging+ (256), Omics (0), and Clinical (618). At the bottom of the page, there are two buttons: 'Edit' and 'Add to Cart'. The 'Add to Cart' button is circled in blue.



### 3. Click “Create Data package/Add data to study”

### 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 expected to release, or publication directly to the underlying subject-level records for the data defined. Automatically, the NDA Study (DOI), which is expected to be referenced in the publication as a persistent link to the supporting dataset.

**NOTE:** This may not represent all available data for these subjects - click "Find All Subject Data" to return all data for these subjects.

**2. Select modality**

**1. All options must be selected**

**Collections by Permission Group**

Collapsible All | Deselect All

Developing Human Connectome Project (dHCP)  
You do not have access to this permission group. You can apply for access at [Developing Human Connectome Project \(dHCP\)](#)

[3955] Developing Human Connectome Project (dHCP)  
Investigators: David Edwards, Jo Hajnal, Daniel Rueckert, Stephen Smith

**Data Structure by Category**

Collapsible All | Deselect All

Adverse Events  
 NICU Episode Summary (190 of 190 subjects available)

Autism Spectrum Disorders  
 Quantitative Checklist for Autism in Toddlers (617 of 617 subjects available)

Checklist  
 Quantitative Checklist for Autism in Toddlers (617 of 617 subjects available)

DTI, MRI, fMRI  
 Image (782 of 782 subjects available)

Demographics  
 NICU Episode Summary (190 of 190 subjects available)  
 Participant Enrollment (984 of 984 subjects available)

Depression  
 Edinburgh Postnatal Depression Scale (874 of 874 subjects available)

Diagnostic  
 NICU Episode Summary (190 of 190 subjects available)

Evaluated Data  
 Processed MRI Data (783 of 783 subjects available)

Eye Tracking  
 Eye Tracking Subject-Experiment (706 of 706 subjects available)

Family  
 Fetal Scan Information (273 of 273 subjects available)  
 Neonatal Scan Information (805 of 805 subjects available)

Personality Questionnaire - Method and External Personality Profile (600 of 600 subjects available)

Dataset - 52404 (85 subjects) - Shared pipeline\_BIDS\_files, 032500  
 Dataset - 52405 (83 subjects) - Shared pipeline\_BIDS\_files, 032600  
 Dataset - 52406 (85 subjects) - Shared pipeline\_BIDS\_files, 032700  
 Dataset - 52407 (92 subjects) - Shared pipeline\_BIDS\_files, 032800  
 Dataset - 52408 (95 subjects) - Shared pipeline\_BIDS\_files, 032900  
 Dataset - 52409 (89 subjects) - Shared pipeline\_BIDS\_files, 033000  
 Dataset - 52410 (92 subjects) - Shared pipeline\_BIDS\_files, 033100  
 Dataset - 52411 (90 subjects) - Shared pipeline\_BIDS\_files, 033200  
 Dataset - 52412 (82 subjects) - Shared pipeline\_BIDS\_files, 033300  
 Dataset - 52413 (84 subjects) - Shared pipeline\_BIDS\_files, 033400



### 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.

### Health

- **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".

The screenshot shows a web interface for data management. At the top, there are buttons for 'Find All Subject Data', 'Return', 'Create Data Package' (highlighted with a red circle), and 'Add Data to Study'. Below this, there are two main panels: 'Collections by Permission Group' on the left and 'Data Structure by Category' on the right. The left panel shows a list of datasets under the 'Developing Human Connectome Project (dHCP)' group, with a list of dataset IDs and subject counts. The right panel shows a tree view of data categories, including 'Adverse Events', 'Autism Spectrum Disorders', 'Checklist', 'DTI, MRI, fMRI', 'Image', 'Demographics', 'Evaluative Data', 'Eye Tracking', 'Family', 'Health', and 'Med History'. The 'Eye Tracking' category is expanded, showing 'Eye Tracking Subject-Experiment (0 of 706 subjects available)'. A yellow box with the text 'Example selection: eye-tracking' and a black arrow points to this option. The 'Create Data Package' button is also highlighted with a red circle.



6. Create a name for your selected data package and select option “include associated files”. Click “Create Data Package”.

Researchers who share data through NDA, or who conduct a secondary analysis on data shared through NDA, are expected as part of the Terms of Use to report their results using the [NDA Study feature](#). An NDA Study links a finding, data release, or publication directly to the underlying subject-level records for the data defined. Automatically, the NDA Study provides attribution (i.e. credit) for those that contributed the data. Each NDA Study is also issued a Digital Object Identifier (DOI), which is expected to be referenced in the publication as a persistent link to the supporting dataset.

**NOTE:** This may not represent all available data for these subjects - click "Find All Subject Data" to return all data for these subjects.

**1. Name your data package**

**2. Select option**

**3. Create Data Package**

7. Pop up window: Click ‘here’ to view the progress of the data package creation or ‘ok’ to stay on the package creation page.

Your request to create a data package was successfully initiated, at any time you can go to the data packages tab on the dashboard to view the status of the data package named **EYETRACKING**. Click [here](#) to navigate to the dashboard.

**OK**

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.



**1. Browse Data packages**

**2. Download data**

The screenshot shows the NDA Download Manager interface. On the left, a tree view under 'My Data Packages' shows a folder 'et\_subject\_experiment01' selected. On the right, a table lists data packages for download. The table has columns for 'Name', 'Path', 'Total Files', 'Total Bytes', 'Files Downloaded', and 'Bytes Downloaded'. Each row has a 'DOWNLOAD' button and a refresh icon. The table shows 10 rows of data packages, all with 1 file and 1b total bytes. Below the table, it indicates 'Disk Space Available on C: is 781.86Gb'.

DOWNLOAD	Name	Path	Total Files	Total Bytes	Files Downloaded	Bytes Downloaded
✓	sub-CC00050XX01.zip	et_subject_experiment01/	1	1b	0	0b
✓	sub-CC00051XX02.zip	et_subject_experiment01/	1	1b	0	0b
✓	sub-CC00052XX03.zip	et_subject_experiment01/	1	1b	0	0b
✓	sub-CC00054XX05.zip	et_subject_experiment01/	1	1b	0	0b
✓	sub-CC00057XX08.zip	et_subject_experiment01/	1	1b	0	0b
✓	sub-CC00058XX09.zip	et_subject_experiment01/	1	1b	0	0b
✓	sub-CC00059XX10.zip	et_subject_experiment01/	1	1b	0	0b
✓	sub-CC00060XX03.zip	et_subject_experiment01/	1	1b	0	0b
✓	sub-CC00061XX04.zip	et_subject_experiment01/	1	1b	0	0b
✓	sub-CC00063AN06.zip	et_subject_experiment01/	1	1b	0	0b

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

The screenshot shows the 'Settings' page in the NDA Download Manager. The 'Settings' tab is selected in the top navigation bar. The main content area is titled 'Settings' and contains the instruction: 'Please select directory into which you wish to download files.' Below this, there is a 'Download Directory' field with the value 'C:\Users\vk12\Download' and a 'CHOOSE DOWNLOAD DIRECTORY' button circled in blue. Other settings include 'Download Batch Size: 50', 'User Download Threshold: 21990.23 GB', 'Local 30-Day Download Volume: 19.12 GB', and 'Local 30-Day Download Volume Remaining: 21971.11 GB'.

## Brain Imaging Data Structure (BIDS)

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



## Frequently asked questions

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

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

### 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 <https://bids-standard.github.io/bids-starter-kit/>

### 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>

<https://nda.nih.gov/user/dashboard/profile.html>

The screenshot shows the NDA user profile page. The page title is "Profile". The username is "Your username". The page contains several form fields for personal information:

- Username: Your username
- First Name: \*
- City: \*
- Work Phone Number: \*
- Email Address: \*
- Last Name: \*
- State or Province: \*
- Postal Code: \*
- Country: \*
- My Institution: \*

There is a "Save" button at the bottom left and a "Reset Password" button at the top right. Annotations include a yellow box labeled "1. Username for Download manager tool" pointing to the Username field, and another yellow box labeled "2. Reset password" pointing to the Reset Password button.