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# DATA ACCESS REQUIREMENTS

**DAC DBG UMC Utrecht**

This document contains the details of the requirements to access a research dataset submitted to a repository and is completed by the researchers involved in the project. The completed ‘Data Access Requirements’, together with the (empty or anonymized) Informed Consent Form used in the study, will be the only information that is used by the Data Access Committee DBG of the UMC Utrecht to judge data access requests that are received, and thus completeness of this form is crucial.

**Note:** In case the **(empty or anonymized) Informed Consent Form** is not send to the DAC (dacdbg@umcutrecht.nl) during submission, the dataset shall not be shared.

**Dataset details**

Submission date *(the date that you send this form to the DACDBG)*:

Dataset EGA ID *(filled in afterwards by the DACDBG)*:

Dataset DACDBG upload ID *(filled in by the DACDBG)*:

Title Dataset *(this title will be visible at the EGA-website)*:

Description Dataset (short description, like 1 or two sentences
*(this description will be visible at the EGA-website)*:

Name of the project that created the dataset
*(Title of the Study: this title will be visible at the EGA-website)*:

Project website *(if not applicable, state N/A)*:

Cooperation with other organizations regarding this dataset? **Yes / No**1)  *if so, which organizations?*:

Data owner *(this is normally the organization – like UMCU - (not the PI for instance))*:

**Contact information**

Name dataset submitter *(The person who will actually provide the data to us (the DAC),
so we can upload the data to the EGA)*:

Email-address dataset submitter:

Name data creator/producer:

Email-address data creator/producer:

Name PI (Primary Investigator):
Email-address PI:

Name Responsible contact for Study:
Email-address Responsible contact for Study:

Informed Consent

The signed Informed Consent Forms regarding the individuals whose data has been included in this dataset are available: **Yes / No**1)

If ‘Yes’, the signed Informed Consent Forms are located at (names and email-addresses):

**Research specific Restrictions** *(based on the DUO codes; see* [*https://ega-archive.org/data-use-conditions*](https://ega-archive.org/data-use-conditions)*)*

**The dataset may be shared and used: …**

|  |  |
| --- | --- |
| * for (all) health/medical/biomedical purposes and other biological research, **including** the study of population origins or ancestry.(DUO:0000042)
 | Yes / No1)  |
| * for (all) health/medical/biomedical purposes and other biological research, **excluding** the study of population origins or ancestry.(DUO:0000006)
 | Yes / No1) |
| * **only** for purposes that are related to the specific disease, namely …(DUO:0000007; [<MONDO-code for specific disease>](https://www.ebi.ac.uk/ols/ontologies/mondo)) 2)
 | Yes / No1)*(if yes, specify by filling in “namely”)* |
| * **only** to the study of population origins or ancestry. (DUO:0000011)
 | Yes / No1) |
| * **only** in studies of a certain research type, namely … (DUO:0000012)
 | Yes / No1)*(if yes, specify by filling in “namely”)* |
| * **only** if the use excludes methods development research (e.g., development of software or algorithms) and only within the bounds of other use limitations. (DUO:0000015)
 | Yes / No1) |
| * **only** for genetic studies (i.e., no phenotype-only research). (DUO:0000016)
 | Yes / No1) |

**Requestor specific Restrictions** *(based on the DUO codes; see* [*https://ega-archive.org/data-use-conditions*](https://ega-archive.org/data-use-conditions)*)*

**The dataset may be shared and used …**

|  |  |
| --- | --- |
| * **only** by not-for-profit organizations (DUO:0000018)
 | Yes / No1) |
| * **only** if the requestor agrees to make the results, of the studies using these data, available to the larger scientific community (publication). (DUO:0000019)
 | Yes / No1) |
| * **only** if the requestor agrees to collaborate with the primary study investigator(s). Therefore, the requestor should contactName: Email-address:(DUO:0000020)
 | Yes / No1)*(if yes, fill in contact information)* |
| * **only** if the requestor provides documentation regarding the approval of the local IRB/ERB for the study these data will be used for. (DUO:0000021)
 | Yes / No1) |
| * **only** by organizations within a specific geographic region, namely …(DUO:0000022)
 | Yes / No1)*(if yes, specify by filling in “namely”)* |
| * **only** if the requestor agrees not to publish results of studies until a specific date, namely …(DUO:0000024)
 | Yes / No1)*(if yes, specify by filling in “namely”)* |
| * **only** for a specific number of months, namely …(DUO:0000025)
 | Yes / No1)*(if yes, specify by filling in “namely”)* |
| * **only** by approved users, namely (names and email-addresses) …(DUO:0000026)
 | Yes / No1)*(if yes, specify by filling in “namely”)* |
| * **only** within an approved project, namely …(DUO:0000027)
 | Yes / No1)*(if yes, specify by filling in “namely”)* |
| * **only** within an approved institution, namely …(DUO:0000028)
 | Yes / No1)*(if yes, specify by filling in “namely”)* |
| * **only** if the requestor agrees to return derived/enriched data to the database/resource, namely …Name: Email-address:(DUO:0000029)
 | Yes / No1)*(if yes, fill in contact information)* |

**License that is applicable on this dataset**

Is there any license applicable on this dataset? Yes / No1)
\* If so, namely:

**Citing and crediting**

In publications, it is mandatory …

* (if applicable) to use citation(s): Yes / No1)
 \* If yes, use the following citation(s):
* to name the data creator: Yes / No1)
* to email the data creator: Yes / No1)

**Other limitations for use / share dataset?** Yes / No1)
\* If yes, namely

**File access**

Receiver of the Data guarantees the below restrictions on file access:

* Data receivers shall agree that they will handle all data in accordance with the GDPR and keep such data confidential.
* Data is not transferrable to third parties. If a third party should be granted access to the Data, the third party should apply through the formal DAC procedure (see below: ‘Process of acquiring access to dataset’).
* If Receiver of the Data is leaving the institute where he/she acquired the Data, Data should be removed from all systems.
* Data receivers to whom the dataset is shared with by the DAC agrees upon the above and is solely responsible for following these restrictions on handling the data.

**Process of acquiring access to dataset**

The access to this dataset can be acquired by contacting the Data Access Committee of DBG via dacdbg@umcutrecht.nl.