

## CBS linkage manual

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## 1. Background

Registries in the Netherlands contain a wide range of data that can be relevant for the purpose of scientific research. These registry data can be linked on a person-level to the researchers' own data, i.e. cohort, trial or biobank data. To link these two data sources, it is necessary to match key identifying information of participants of your own research data with the registry data. Generally, research on linked data can be performed on an external research environment of the respective registry, however in some cases the registry data can be requested, received and used outside the registry environment. The linkage of data with these registries for scientific research purpose can happen only under certain conditions, that are provided by national legislation and specific laws.

## 1. Objective

This manual provides a practical guide of these conditions and describes the steps to follow during preparation to link your own (research) data in the Amsterdam UMC with data from Statistics Netherlands.

## 2. Linking with CBS

Statistics Netherlands (CBS) provides linkable data on person- and address-level for Dutch universities, university hospital, and scientific organizations within legislative boundaries.

### 2.1. Linking with microdata

#### 2.1.1. Background microdata

The microdata from CBS are organized in different datasets, each of which contains information regarding various areas, such as social economic status, hospital data (e.g. diagnoses of hospital admission), medication data and cause of death. All datasets clustered within specific domains can be found here: [Catalogus microdata \(cbs.nl\)](#). To support findability, ODISSEI, the national research infrastructure for the social sciences in the Netherlands, has developed a portal in which metadata of all microdatasets can be browsed by search terms: [ODISSEI Portal](#)

#### 2.1.2. Procedure

All steps described below are also accessible in an [interactive infographic](#).

#### Step 1. Informed consent

CBS also allows researchers to link their own (cohort) research data<sup>1</sup> to CBS microdatasets.

- a. First, as the researcher and project leader, it is your responsibility to ensure you have proper informed consent from your participants or patients that must explicitly allow the linkage between their data with (CBS) microdata. It is important to note that in case you are willing to link your research data with microdata sets provided from other sources within the CBS environment, you need explicit informed consent for the linkage with these datasets (such as Vektis health insurance data). If you are unsure

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<sup>1</sup> NB. It is also possible to perform analyses on only CBS microdata. You can skip the steps on informed consent and linking variables.



whether the consent meets the requirements, consult the privacy officer (via the [Serviceportal](#)) for clarification.

NB. Exceptions may arise. For example, when a cohort is based on the ‘no objection’ principle. Consultation with the privacy officer, METC and a jurist from CBS is needed.

- b. To link your data with the microdata sets, you will need to provide CBS with a dataset containing, between the other variables you plan to upload, the following linking variables (see step 10 for the procedure to upload these variables and dataset). These variables are essential for accurate matching and include:

- i. Date of birth
- ii. Sex
- iii. Date of death (if applicable)
- iv. Postal code (4 or 6 digits)
- v. House number
- vi. Year or date when the address was valid

These linking variables must be included in the same dataset as the other variables you plan to upload (cohort-specific variables). More information can be found [here](#).

- c. Please note that CBS uses a deterministic linkage method, meaning they only link records where a 100% match is confirmed. This may result in some participants or patients being excluded if a match cannot be confirmed. For example, if your datasets includes many same-sex twins, linking may be more challenging due to similarities in their linking variables.

## Step 2. Institutional authorization

The institution from which you conduct your research must be authorized by CBS. For Amsterdam UMC, the authorization is already in place, so you can proceed directly to Step 3. You can find current authorized institutions [here](#). Specific institutions are able to apply for this authorization which is valid for three years and then renewal might be requested.

## Step 3. CBS microdata account

To link your research data with CBS registry data, you need a CBS microdata account. You can register on the [CBS-microdata portal](#). After registration, you will receive a confirmation email from CBS and can activate two-factor authentication.

## Step 4. Start a new project

Before you can link your research data with CBS microdata, you first need to start a new project in your CBS microdata account. In the [CBS-microdata portal](#), you need to provide some basic information such as title of the project, start and end date, and some billing information. Be aware that you can only open a new project when you are also the project leader of said project.

## Step 5. Upload study documents

After registering your project, you have to provide additional information in the section ‘Documentation for project agreement’. These include:

- a. The purpose of the project;
- b. Your publication plan (results from your research using CBS microdata should be made publicly available by for example publishing your results in a scientific journal). Here you have to indicate in what form you will publish the results (e.g. a scientific article



or policy report), when the intended publication date is, and where you will publish this (e.g. a scientific journal or other platforms);

- c. The GDPR basis. Here you have to fill in on which legal grounds your institution (and therefore you as a researcher) are going to conduct research on CBS microdata. You can choose either:

- GDPR article 6 paragraph 1 e (public interest). This legal basis allows processing of (personal) data when it is necessary the research is carried out in the public interest or as part of official duties. This is typically used by public authorities acting under law.

or

- GDPR article 6 paragraph 1 f (legitimate interest). This legal basis allows processing of (personal) data when there is a justified private or organizational interest. This is mainly used by private companies and public authorities when they are not acting under official authority.

As you are going to conduct research as an employee of an academic hospital, your research will most likely fall under the Higher education and Research ACT (WHW). If this applies to your institution where you are performing your research, you can choose GDPR article 6 paragraph 1 e. Please note it is always necessary to have this confirmed by a privacy officer. You can contact Team Privacy via the [Serviceportal](#).

### Step 6. Add team members

In the next section in the portal, you can add team members. It is mandatory to add a member from your organization that is authorized to sign documents and legal contracts. Please note a difference in type of researcher:

- Active user: this researcher will actively work on the project and uses the microdata. This person will receive a token (explained in step 4) and pays a user fee. Active users can discuss data only with onlookers (i.e. the other type of researcher).
- Onlooker: this researcher is only allowed to look in on the data together with the active user and does not pay a fee.

### Step 7. Micro data selection and research data use

Lastly, you can fill in which microdatasets will be used. Here you can also indicate your intention to upload your own (research) data for this project. You can explore available microdatasets through:

- [CBS Microdata Catalogue](#)
- [ODDISEI Portal](#) (searchable metadata)

When your project information is complete, you can submit your project for review in the portal.

### Step 8. CBS expert meeting

After you have submitted your project for review in the portal, , CBS will review your project. The project application will also be assessed for feasibility and GDPR compliance, among other



things. CBS (specifically your allocated contact person) will invite you for a meeting with CBS experts (based on your selected microdatasets) to confirm that your selected microdatasets align with your research question. Also, a cost estimate will be provided. The expenses involved in carrying out research independently are influenced by factors such as the numbers of researchers, the variety of files, and the project's duration. An overview of all costs can be found [here](#).

### Step 9. Contract and access

After steps 4-8, you will receive a contract from CBS. You need to send this contract to the Legal department (via [Suez](#); you can find a guide [here](#)) and the appropriate team member has to sign and return the contract. As a researcher you also have to sign a confidentiality form and do a privacy awareness test. You will also receive information on a token you will need to [log into the Remote Access environment](#).

### Step 10. Upload research data and linkage

CBS will provide you with login credentials to access their secure server to upload your own (research) data. You will be requested to explain why the data you are uploading are needed to answer the research questions in your project (the research purpose) and also who is performing the upload.

Your dataset should be formatted in one of the following file types:

- i. SPSS (.sav)
- ii. CSV (.csv)
- iii. ASCII (.txt)

If the uploaded datasets are in .CSV or ASCII fixed format, you will have to include an explanation with the following information:

- the number of records;
- a record description;
- a description per variable (label);
- where applicable, a code book (the possible values of the variable with a description).

Besides this, it is necessary to fill in and send the "Upload information form".

This form must be saved with the following name: *uploadXXXXJJJMMDD.xlsx* (XXXX=project number, JJJMMDD is for example 20180703) and include the document in the zip file of the upload.

To send the files, you can log in in the CBS' secure upload facility with the received login codes. This can be found at the following link: <https://databestanden.cbs.nl>. You must then zip the data file(s), the Upload information form, the code book and the variable description, and finally name the zip file with the project number of your microdata project (*projectnumber.zip*).

Once uploaded, CBS will process your data and create a dataset with a unique pseudonymized linking variable for every participant or patient: The RINPERSOON number, in which key identifying information of each person are converted. This linking variable can be used to link to the requested microdatasets in the remote access environment.

