



EURO-NMD Registry - Quick Start Guide

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1 About EURO-NMD Registry

The ERN EURO-NMD Registry collects standardised, long-term data on patients with rare neuromuscular diseases, diagnosed or undiagnosed. The EURO-NMD Registry is maintained on REDCap (Research Electronic Data Capture), a secure web application for building and managing online surveys and databases developed by Vanderbilt University (USA)¹. The REDCap server for the EURO-NMD Registry is housed in a secure central facility of the University Medical Center Freiburg (UKLFR) and maintained by UKLFR IT staff.

2 Requesting access

Legal basis for access to the EURO-NMD Registry is a **data sharing agreement (DSA)**. Once the DSA is signed, EURO-NMD coordination asks the ERN main contact person for each ERN-member health care provider as defined by the European Commission (HCP) to

- identify which data access groups (DAG) are needed for this HCP for the registry
- for each DAG, nominate a main contact person for the EURO-NMD Registry (by default, it will be the ERN main contact person for all DAGs associated to this HCP) and a backup main contact

A **data access group (DAG)** corresponds to an organisational entity that wants to manage its own collection of patient records in the registry. Every patient record in the registry is assigned to exactly one DAG. Only registry users with access permissions for this DAG will be able to access its patient records.

A DAG could correspond to a **unit**, i.e. services/departments inside a hospital (e.g. paediatric and adult). This applies mostly when 1 HCP = 1 hospital. DAGs for units should be reduced to a minimum.

A DAG could also instead correspond to a **site**, i.e. a hospital that is part of an HCP that joined the ERN as a consortium of multiple hospitals.

The **DAG's main contact person** does not have to be a domain expert for neuromuscular diseases and does not have to be authorised to sign, etc. However, this person should know the people of the DAG who work with the registry, as this person will decide who should have which access permissions for working with the patient records of this DAG. This person also forwards communication about the registry to the appropriate people at the DAG.

If the DAG's main contact person or backup or ERN main contact person for an HCP changes, the HCP informs ERN coordination. ERN coordination confirms the change and informs UKLFR.

Patients (data subjects) will not receive an account for the EURO-NMD Registry. Instead, for a future release of the EURO-NMD Registry, we plan to use REDCap-Surveys to allow patients to contribute to the data collection. Although we already prepared and tested the survey-functionality for some data collection instruments, for now all surveys are in offline-status because the workflows for distributing survey-invitations to patients have not yet been fully defined and documented. Until that is done, data providers can access the potential surveys in the same way they access all the other data collection instruments as logged in users on the REDCap-system.

¹ <https://www.project-redcap.org/>, accessed 30.10.2023



In contrast to data access groups, **roles** in REDCap do not define what records a user can see but instead what users can do with those records and in general what REDCap features are accessible for them. REDCap-accounts can be assigned to exactly one role.

The following settings are applicable to all roles:

- Data Viewing Rights for all data collection instruments (forms)
- Access to the *Data Comparison Tool* to identify similar records and potential duplicates.
- Access to *Logging* (REDCap-internal audit trail)
- Access to the REDCap *File Repository*. This is used to share user manuals, documentation and data reports. Within the File Repository, there is a public space and a space with restricted access for each DAG. Subject-level data of a DAG must never be shared in the public space of the file repository and can only be shared within the restricted space of this DAG.
- Right to execute *Data Quality Rules* to quickly identify records that do not meet a particular predefined rule.
- *Field Comment Log*

So far, the following features are not used in the EURO-NMD Registry and no role has access:

- *Survey Distribution Tools*
- *Alerts & Notifications*
- *Calendar*
- *REDCap Mobile App*
- *MyCap App*

Role “Admin”

Has full access to all REDCap features (including project design and setup and the right to assign users to roles and to DAGs). They cannot enter, modify or delete data but have read-only access to all data collection instruments and all records. They are allowed to execute data exports for the entire registry (all DAGs). Typically, users of this role are not assigned to a DAG and should be able to see all records of all DAGs.

Role “Data Entry”

Can create, edit, rename and delete records. Cannot export data. Cannot import data.

Role “Data Entry and Import”

Can create, edit, rename and delete records. Cannot export data. Can import data using the Data Import Tool.

Role “Data Entry and Export”

Can create, edit, rename and delete records. Can export data via Data exports, Reports, and Stats. Cannot import data.

Role “Data Entry, Import and Export”

Can create, edit, rename and delete records. Can import data using the Data Import Tool. Can export data via Data exports, Reports, and Stats.

Role “Data Viewer”

Has read-only access. Cannot create, edit or delete records. Cannot export data.

Role “Data Viewer and Export”

Has read-only access. Cannot create, edit, rename or delete records. Can export data via Data exports, Reports, and Stats.



Access to the REDCap system and authorisations for EURO-NMD Registry are only granted for limited time to ensure regular review of privileges (IT security, data protection). The DAG's main contact person is automatically notified before the system access of their team members expires.

Once ERN coordination confirmed that DSA is signed and confirmed the DAG(s) and main contact(s) of an HCP, the registry host (UKLFR) sets up the DAG on the REDCap platform and creates REDCap-accounts and access to the registry as defined by the DAG's main contact person.

If access rights for their team are to be extended, added, modified or withdrawn, the DAG's main contact person informs EURO-NMD coordination.

REDCap-accounts are bound to a person and cannot be shared. To set up REDCap-accounts and grant access to the EURO-NMD Registry, UKLFR needs at least:

- full name of the user
- business e-mail address of the user (private e-mail address not allowed – IT security and data protection)
- data access group for the user (name of your site/unit in the registry)
- role for the user (one of the roles listed above)
- start date for the access to the EURO-NMD Registry (if not provided, UKLFR will grant access immediately)
- expiration date for the access to the EURO-NMD Registry. Maximum 3 years in future. If not defined by request, UKLFR will default to 3 years. Users can easily be reactivated after that date if needed.



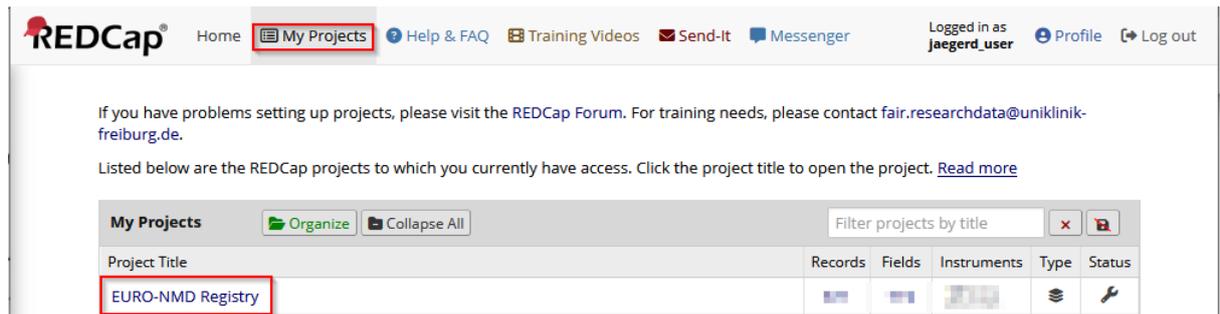
3 REDCap User Interface Overview

Vanderbilt University provides several helpful video-tutorials for REDCap:

- ["Brief Overview"](#), accessed 30.10.2023
- ["Data entry overview"](#), accessed 30.10.2023

Here again some important points about the REDCap user interface for reference.

When you login to the REDCap-system of the University Medical Center Freiburg (UKLFR) that hosts the EURO-NMD Registry, you will see the registry under the tab "My Projects":



To open the registry, simply click on "EURO-NMD Registry".

Once inside the EURO-NMD Registry, you see the **menu (navigation)** on the left and the **workspace** on the right:



The content of the workspace depends on the page selected in the menu.

The items listed on the menu depend on the access level for your account on this project. If you need access to a tool that is not listed on your menu, please follow the instructions for requesting access as described above.

Under the menu's "Project Home and Design"-section you find a **Codebook** with a human-readable version of the **registry's metadata**. The Codebook lists all implemented data collection instruments, the fields they contain and the formats and codes for their values.

The main area used for **data entry and data access** is the menu's "Data Collection"-section. The "Record Status Dashboard" displays the records that have already been created, the available data collection instruments (forms) and the status of each form (coloured status icons).

In the EURO-NMD Registry, each REDCap-record corresponds to a patient. The REDCap-"Patient ID"



is a unique pseudonym that REDCap automatically creates for every newly added patient in the registry. Data providers must document the REDCap-“Patient ID” within their local patient file to be able to identify the patient at a later point.

From the “Record Status Dashboard”, you can navigate to the “**Record Home Page**” of each patient by clicking on their REDCap-“Patient ID” or you can open a specific form of this patient by clicking on this form’s coloured icon. The “Record Home Page” basically displays the same information and links as the “Record Status Dashboard” with the difference that this view is focused on a single patient.

On the “**Add / Edit Records**”-page you can open an existing record by first selecting the disease group and then the REDCap-“Patient ID” or you can use “Data Search” to type a keyword (e.g. name of a diagnosis) and open a record by clicking on one of the returned matches.

For adding a new record, you again select the applicable disease group first and then click on “Add new record for the selected arm above”. See below in [section “Disease groups”](#) for a description of the disease groups and how to assign patients to the correct group.

Under the menu’s “**Applications**”-section you find several helpful tools to work with data in the registry. For example, on the page “Data Quality” you can access a set of predefined data quality rules and quickly identify records that do not meet a particular rule.

“**Project Dashboards**” provide access to simple summary statistics and figures.

The menu-section “**Help & Information**” provides access to REDCap-help and tutorials. It is not specific to the EURO-NMD Registry.

4 EURO-NMD Registry structure

4.1 Disease groups

The EURO-NMD Registry is structured into five subsets that each represent one of the specialist disease groups of ERN EURO-NMD: Neuropathies, Myopathies, Mitochondrial Diseases, Neuromuscular Junction Disorders, Motoneuron Diseases. In addition, there is a subset for „Undiagnosed Cases“.

Many instruments and fields are shown or hidden depending on the disease group. Use the "Arm 6: Undiagnosed Case" only for patients you cannot assign to any of the other disease groups. If you only know the disease group and, for example, do not yet have a genetic diagnosis or cannot give an exact ORPHAcode for the diagnosis, still use the applicable disease group.

4.2 Events and data collection instruments

Events represent points in time where a certain set data collection instruments (“forms”) should usually be completed. For the EURO-NMD Registry, three events were created: “Enrolment and first visit”, “Visit” and “Visit-unrelated”.

“Enrolment and first visit” offers all data collection instruments that are also available under the “Visit”-event but additionally contains a form “Consent” for the data usage specifications and a form “Baseline” for some retrospective questions about care pathway and the current situation of the patient at signup in the registry. The “Consent”-form can be filled multiple times in case that a patient changes their preferences.

The “Visit”-event contains all data collection instruments that are relevant for follow-ups. Here, the entire event can be repeated as many times as needed (desired are annual updates). Even if, in deviation from the event logic, a date of data collection can also be specified in each individual form,



it is desirable for the analysability of the data that only data that are in a reasonably close temporal context are stored under the same instance of a "visit" event.

The "Visit-unrelated"-event covers data items whose collection does not necessarily coincide with a visit, for example: Results of genetic testing, medication and a dedicated form for end of data collection.

NOTE: In the EURO-NMD Registry, there are no repeatable forms in repeatable events. Either the form is repeatable or the event is repeatable or neither the form nor the event are repeatable.

5 Accessing the registry

1. Navigate to <https://stuz-redcap.ukl.uni-freiburg.de/>
2. Once logged in you should see a project "EURO-NMD Registry". Click on that project.

The screenshot shows the REDCap user interface. At the top, there is a navigation bar with the REDCap logo, 'Home', 'My Projects', '+ New Project', 'Help & FAQ', 'Training Videos', 'Send-It', and 'Messenger'. On the right, it says 'Logged in as jaegerd_user_tc1'. Below the navigation bar, a message states: 'Listed below are the REDCap projects to which you currently have access. Click the project title to open the project. [Read more](#)'. The main content area features a 'My Projects' section with a search bar and a table of projects. The table has columns for 'Project Title', 'Records', 'Fields', 'Instruments', 'Type', and 'Status'. The 'EURO-NMD Registry' project is highlighted in blue.

| Project Title | Records | Fields | Instruments | Type | Status |
|-----------------------------------|---------|--------|-------------|------|--------|
| EURO-NMD Registry | 63 | 557 | 9 forms | | |

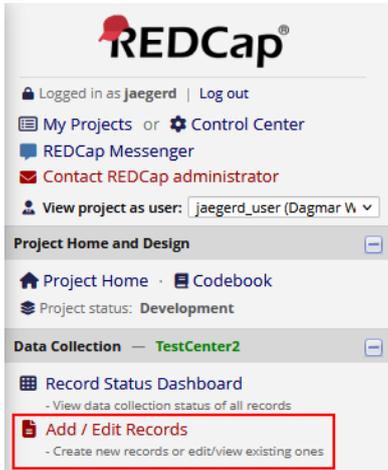


6 Providing data to the registry

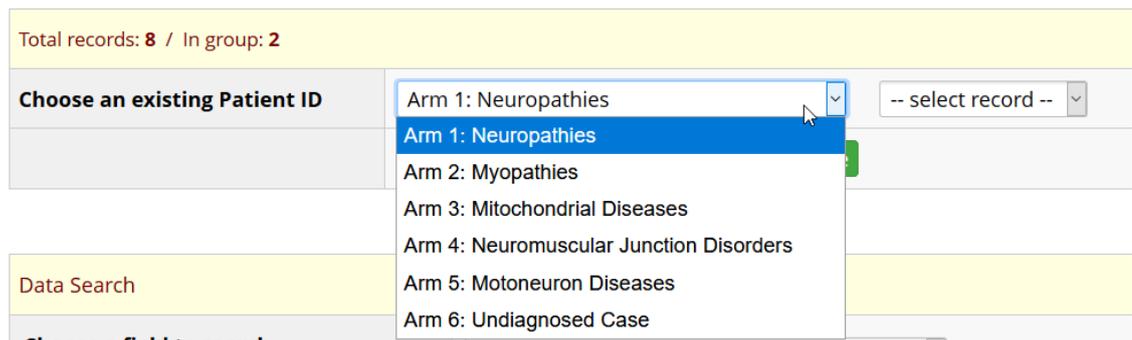
6.1 Manual Data Entry

6.1.1 Manually adding a new patient

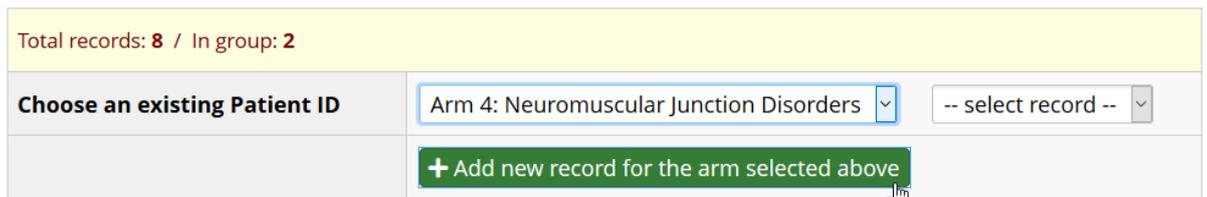
1. click on „Add / Edit Records“ on the left navigation:



2. Choose the applicable disease group from the dropdown:



3. Click on “Add new record for the selected arm above”:



Note: The newly created patient will only be permanently saved in the system if at least one form is subsequently filled in and saved.

4. At the enrolment event you will typically start by filling the “Consent”-form. To do this, simply click on the grey dot in the relevant table field:

NEW Patient ID 309-47

Arm 1: Neuropathies

| Data Collection Instrument | Enrolment and first visit | Visit-unrelated | Visit |
|---|---------------------------|-----------------------|-----------------------|
| Consent | <input type="radio"/> | | |
| Baseline | <input type="radio"/> | | |
| Visit Data | <input type="radio"/> | | <input type="radio"/> |
| Genetic Diagnosis: Changes in nuclear DNA | | <input type="radio"/> | |



5. Note down the automatically generated “Patient ID” (REDCap record_id) within your local patient file. Otherwise you may not be able to identify the patient at a later point.
6. Once you completed the data entry for this form, you can set the form status...

Form Status

Complete? Incomplete Incomplete Unverified Complete

...and save the data. “Save & Exit Form” will take you back to the Record Home Page of that patient.

Save & Exit Form **Save & ...** **-- Cancel --**

- Save & Stay
- Save & Go To Next Form
- Save & Exit Record
- Save & Go To Next Record



6.1.2 Manually adding a new instance of a repeatable form

Some data collection instruments are repeatable within an event. For example, the “Medication”-form is designed to be repeated for each interval of administration of a specific treatment and dosage. To add a new instance of a form

1. Navigate to the “Record Home Page” of the relevant patient
2. Click on the + Icon for the relevant form

Patient ID 3
Arm 3: Mitochondrial Diseases

| Data Collection Instrument | Enrolment and first visit | Visit-unrelated | + Add new Visit 2021-06-28 |
|---|------------------------------------|------------------------------------|----------------------------------|
| Consent | <input checked="" type="radio"/> + | <input type="radio"/> | |
| Baseline | <input checked="" type="radio"/> | <input type="radio"/> | |
| Visit Data | <input checked="" type="radio"/> | <input type="radio"/> | <input checked="" type="radio"/> |
| Genetic Diagnosis: Changes in nuclear DNA | <input type="radio"/> | <input type="radio"/> | |
| Genetic Diagnosis Changes in mitochondrial DNA | <input type="radio"/> | <input checked="" type="radio"/> + | |
| Negative Genetic Tests (only when no genetic diagnosis) | <input type="radio"/> | <input type="radio"/> | |
| Medication | <input type="radio"/> | <input checked="" type="radio"/> + | |
| WHODAS 2.0 12-item (survey) | <input checked="" type="radio"/> | <input type="radio"/> | <input checked="" type="radio"/> |
| PGI-C (only available if date of birth filled in Baseline) (survey) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| End of Data Collection | <input type="radio"/> | <input type="radio"/> | |

Note: The + Icon is only available if one instance of the form has already been saved earlier.

3. Enter data and save the form with the applicable status via “Save and exit form”
4. Back on the Record Homepage, you will see additional overview-tables for all instances of repeatable forms, e.g.

Repeating Instruments

| Medication | | + Add new |
|--|---|-----------|
| Unscheduled (Arm 5: Motoneuron Diseases) | | |
| (2) | | |
| 1 | <input checked="" type="radio"/> Nusinersen (12mg; 1 once): 01.04.2021 - 01.04.2021 | |
| 2 | <input checked="" type="radio"/> Aspirin (300mg; 1 per_day): 01.07.2021 - ongoing | |
| + Add new | | |



6.1.3 Manually adding a new “Visit”-event

Note: This option is only available if you have already edited and saved at least one form under the first “Visit”-event.

1. Navigate to the “Record Home Page” of the relevant patient
2. In the “Visit”-column of the overview-table with all available data collection instruments, click on “+ Add new”

Patient ID 3
Arm 3: Mitochondrial Diseases

| Data Collection Instrument | Enrolment and first visit | Visit-unrelated | + Add new Visit 2021-06-28 |
|--|------------------------------------|------------------------------------|----------------------------------|
| Consent | <input checked="" type="radio"/> + | | |
| Baseline | <input checked="" type="radio"/> | | |
| Visit Data | <input checked="" type="radio"/> | | <input checked="" type="radio"/> |
| Genetic Diagnosis: Changes in nuclear DNA | | <input type="radio"/> | |
| Genetic Diagnosis Changes in mitochondrial DNA | | <input checked="" type="radio"/> + | |
| Negative Genetic Tests (only when no genetic diagnosis) | | <input type="radio"/> | |
| Medication | | <input checked="" type="radio"/> + | |
| WHODAS 2.0 12-item <small>(survey)</small> | <input checked="" type="radio"/> | <input type="radio"/> | <input checked="" type="radio"/> |
| PGI-C (only available if date of birth filled in Baseline) <small>(survey)</small> | <input type="radio"/> | | <input type="radio"/> |
| End of Data Collection | | <input type="radio"/> | |

3. Open the “Visit Data” form under the newly added “Visit”-event by clicking on the grey icon:

Patient ID 3
Arm 3: Mitochondrial Diseases

| Data Collection Instrument | Enrolment and first visit | Visit-unrelated | Visit 2021-06-28 (#1) | ✘ (#2) |
|---|------------------------------------|-----------------------|----------------------------------|-----------------------|
| Consent | <input checked="" type="radio"/> + | | | |
| Baseline | <input checked="" type="radio"/> | | | |
| Visit Data | <input checked="" type="radio"/> | | <input checked="" type="radio"/> | <input type="radio"/> |
| Genetic Diagnosis: Changes in nuclear DNA | | <input type="radio"/> | | |

4. Enter data and save the form with the applicable status via “Save and exit form”.
5. Back on the Record Home Page, the new “Visit”-event will now display the date of visit that you entered in the “Visit Data” form.
6. Now, continue to fill other forms applicable to this follow-up.



6.2 Data Import Tool

Manual data entry is not the only way to provide data to the EURO-NMD Registry. You can also bulk-upload data by importing a CSV-file in a specific format to REDCap as logged-in user. Manual data entry and import through REDCaps data import tool can also be combined.

Please note that the CSV-import is most useful if you are capable of generating the CSV from other data sources in a structured, ideally (semi-) automated way. If the correctly formatted CSV for data import would have to be created manually, then manual data entry is probably much easier, faster and reliable.

The generation of the correctly formatted CSV requires additional training and skills. Only trained users with the required skills should be granted access to the data import tool. The use of the data import tool also requires good planning and well defined workflows at the data provider to avoid accidental overwriting, duplication of records and mismatching values to IDs and events.

6.2.1 Adding new patients via CSV-upload

Let's start with the most simple possible scenario: Adding new data for patients that are not yet included in the EURO-NMD Registry and only for one point in time, only for the first instance of the "Consent"-form in the non-repeatable "Enrolment and first visit"-event. To make the example more readable, we will not import all fields of the consent-form but limit the import to *date_of_consent* and the form-status *consent_complete*.

Assume we want to enrol three new patients in the EURO-NMD Registry with the following original data available at the treating health care provider:

| pid | diagnosis_orpha | diagnosis_name | patient_name | consent_date |
|-------|-----------------|-----------------------------------|--------------|--------------|
| 93456 | 97229 | Riboflavin transporter deficiency | John Doe | 23.08.2023 |
| 93470 | 550 | MELAS | Jane Foo | 03.09.2023 |
| 93499 | 481 | Kennedy disease | Larry Loe | 12.10.2023 |

Table 1: Exemplar patient data for consent in the local database of the treating healthcare provider

Meaning of the columns in table 2:

- pid: Patient ID in local database (e.g. hospital information system)
- patient_name: Full name of the patient
- consent_date: Date on which this patient signed the written informed consent for the EURO-NMD Registry

Before this dataset can be imported into the EURO-NMD Registry, they need to be transformed into the required format:

| record_id | redcap_event_name | redcap_repeat_instrument | redcap_repeat_instance | date_of_consent | consent_complete |
|-----------|--------------------------|--------------------------|------------------------|-----------------|------------------|
| 1 | enrolment_and_firs_arm_1 | consent | 1 | 2023-08-23 | 0 |
| 2 | enrolment_and_firs_arm_3 | consent | 1 | 2023-09-03 | 0 |
| 3 | enrolment_and_firs_arm_5 | consent | 1 | 2023-10-12 | 0 |

Table 3: Exemplar patient data for consent based on table 4, in the required format needed for CSV-import into EURO-NMD Registry



Meaning of the columns table 5:

- **record_id**: placeholder-values that will later be automatically replaced by REDCap during the import (only in case of newly added patients, otherwise must provide REDCap-record_id of existing patient-record here). Best practice is not to use the original patient identifier as in the source data here because later during the data-import-dialogue there is a risk that the user forgets to indicate that REDCap should replace this ID and force auto-numbering. This poses the risk of re-identification and incorrect internal numbering in REDCap, which must be avoided as a matter of urgency.
- **redcap_event_name**: disease-group-specific name of the “Enrolment and first visit”-event. This field controls the disease-group-assignment of the newly added patients. Allowed options for this column can be looked up the REDCap-internal Codebook of the EURO-NMD Registry under the field name “disease_group”.
- **redcap_repeat_instrument**: Name of the data collection instrument (form) that data will be imported to. Allowed options for this column can be looked up the REDCap-internal Codebook of the EURO-NMD Registry by clicking on “Collapse all instruments”

| # | Variable / Field Name | Field Label <small>Field Note</small> | Field Attributes (Field Type, Validation, Choices, Calculations, etc.) |
|---|-----------------------|--|--|
|---|-----------------------|--|--|

[^ Collapse all instruments](#)

and then taking the contents of the bracket after the name of the form:

| # | Variable / Field Name | Field Label <small>Field Note</small> | Field Attributes (Field Type, Validation, Choices, Calculations, etc.) |
|---|--|--|--|
| | Instrument: Consent (consent) | | v Expand |
| | Active languages: None | | |
| | Instrument: Baseline (baseline) | | v Expand |
| | Active languages: None | | |
| | Instrument: Visit Data (visit_data) | | v Expand |
| | Active languages: None | | |

- **redcap_repeat_instance**: Number of the instance of a repeatable form or event. In this example for the registration of new patients in the registry, none of the patients already has data stored for a consent-form so that we need to add data for the first instance of the consent form.
- **date_of_consent**: Date (format: yyyy-mm-dd) on which this patient signed the written informed consent for the EURO-NMD Registry. The required date-format can be looked up the REDCap-internal Codebook of the EURO-NMD Registry in the column “Field Attributes (Field Type, Validation, Choices, Calculations, etc.)”. All date-fields in the registry require “date_ymd” (format: yyyy-mm-dd) as in this example.
- **consent_complete**: form-status of the “Consent”-form for the import-data. These fields for form-status are always called “<instrument-name>_complete” where instrument-name is the same as the earlier mentioned value for redcap_repeat_instrument. The allowed options can be looked up the REDCap-internal Codebook of the EURO-NMD Registry. In the example, we provide a status 0 (“Incomplete”) because we did not provide data for all fields in the „Consent“-form.

Here table 6 as a possible CSV that could be used for the data import:

```
record_id,redcap_event_name,redcap_repeat_instrument,redcap_repeat_instance,date_of_consent,consent_complete
1,enrolment_and_firs_arm_1,consent,1,2023-08-23,0
2,enrolment_and_firs_arm_3,consent,1,2023-09-03,0
3,enrolment_and_firs_arm_5,consent,1,2023-10-12,0
```



To import this CSV into the EURO-NMD Registry, you have to:

- Open “Data Import Tool” from the “Applications”-section of the left menu.
- Provide the following settings for adding new patients to the registry:

Record format: The file to be uploaded has its records stored as separate Rows ▼

Format for date and datetime values: DD/MM/YYYY or YYYY-MM-DD ▼

Allow blank values to overwrite existing saved values? No, ignore blank values in the file (default) ▼

Name the imported records automatically (force record auto-numbering) ? Yes, rename all record names in uploaded file ▼

Choose the delimiter for the uploaded file: Comma (,) ▼

Upload your CSV file:

Durchsuchen... Keine Datei ausgewählt.

Upload File

- Record format: Rows
 - Format for date and datetime values: MM/DD/YYYY or YYYY-MM-DD
 - Allow blank values to overwrite existing saved values? No, ignore blank values in the file (default)
 - Name the imported records automatically (force record auto-numbering): Yes, rename all record names in uploaded file**
 - Choose the delimiter for the uploaded file: Comma (,)
- Attach the CSV-file to the upload under “Upload you CSV file”

Upload your CSV file:

Durchsuchen... EURONMDRegistry_ImportTemplate_consent_simple_2023-10-31.csv

- Click on “Upload File”
- Now, you should see a page to review the provided data with a “Data Display Table”:

✔ **Your document was uploaded successfully and is ready for review.**
You are now required to view the Data Display Table below to approve all the data before it is officially imported into the project. Follow the instructions below.

Instructions for Data Review

The data you uploaded from the file is displayed in the Data Display Table below. Please inspect it carefully to ensure that it is all correct. After reviewing it, **click the 'Import Data' button at the bottom of this page** to import this data into the project.

KEY for Data Display Table below

Black text = New Data

Gray text = Existing data (will not change)

(Red text) = Data that will be overwritten

| DATA DISPLAY TABLE | | | | | |
|---|--------------------------|------------------------|--------------------------|-----------------|------------------|
| record_id | redcap_repeat_instrument | redcap_repeat_instance | redcap_event_name | date_of_consent | consent_complete |
| 309-47 <small>(tentative new record)</small> | consent | 1 | enrolment_and_firs_arm_1 | 2023-08-23 | 0 |
| 309-48 <small>(tentative new record)</small> | consent | 1 | enrolment_and_firs_arm_3 | 2023-09-03 | 0 |
| 309-49 <small>(tentative new record)</small> | consent | 1 | enrolment_and_firs_arm_5 | 2023-10-12 | 0 |

- Thoroughly check the imported data in the overview.
 - If you spot problems in the data import, cancel the import by clicking on “Cancel”:

Do you wish to import the new data (displayed above) into the project?
(Click the button below to import the data.)

Import Data Cancel

Then edit the provided CSV as needed and try again.



- b. If all data in the overview is correct then click on “Import Data”:

Do you wish to import the new data (displayed above) into the project?
(Click the button below to import the data.)

Import Data Cancel

- REDCap should now display “Import successful”:

Import Successful! 3 records were created or modified during the import.

The data you uploaded from the file was successfully imported into the project. If you wish to import more data, you may use the box above to select another file on your computer.

NOTE: Since you elected to force record auto-numbering, listed below are the record names you submitted and also what they were renamed to during the import process. Since the uploaded record names are not stored anywhere in REDCap, it is not possible to download the table below, but instead **you may copy and paste the table below** to Excel or other program to keep for reference.

| Uploaded record name | Saved record name |
|----------------------|-------------------|
| 1 | 309-47 |
| 2 | 309-48 |
| 3 | 309-49 |

- Note down the automatically generated “Patient ID” (REDCap record_id) within your local patient file. Otherwise you may not be able to identify the patient at a later point.
- Check whether the imported data are also correct in REDCap
 - a. via “Record Status Dashboard”

Arm 1: Neuropathies Arm 2: Myopathies
Arm 5: Motoneuron Diseases Arm 6: Undia

Enrolment and first visit

| Patient ID | Consent | Baseline | Visit Data | WHODAS 2.0 12-item |
|------------|---------|----------|------------|--------------------|
| 11 | + | + | + | + |
| 12 | + | + | + | + |
| 13 | + | + | + | + |
| 309-47 | + | + | + | + |
| 309-48 | + | + | + | + |
| 309-49 | + | + | + | + |
| 309-50 | + | + | + | + |
| 309-51 | + | + | + | + |
| 309-52 | + | + | + | + |
| 309-53 | + | + | + | + |
| 309-54 | + | + | + | + |
| 309-55 | + | + | + | + |
| 309-56 | + | + | + | + |
| 309-57 | + | + | + | + |
| 309-58 | + | + | + | + |
| 309-59 | + | + | + | + |
| 309-60 | + | + | + | + |
| 309-61 | + | + | + | + |
| 309-62 | + | + | + | + |
| 309-63 | + | + | + | + |
| 309-64 | + | + | + | + |
| 309-65 | + | + | + | + |
| 309-66 | + | + | + | + |
| 309-67 | + | + | + | + |
| 309-68 | + | + | + | + |
| 309-69 | + | + | + | + |
| 309-70 | + | + | + | + |
| 309-71 | + | + | + | + |
| 309-72 | + | + | + | + |
| 309-73 | + | + | + | + |
| 309-74 | + | + | + | + |
| 309-75 | + | + | + | + |
| 309-76 | + | + | + | + |
| 309-77 | + | + | + | + |
| 309-78 | + | + | + | + |
| 309-79 | + | + | + | + |
| 309-80 | + | + | + | + |
| 309-81 | + | + | + | + |
| 309-82 | + | + | + | + |
| 309-83 | + | + | + | + |
| 309-84 | + | + | + | + |
| 309-85 | + | + | + | + |
| 309-86 | + | + | + | + |
| 309-87 | + | + | + | + |
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| 309-91 | + | + | + | + |
| 309-92 | + | + | + | + |
| 309-93 | + | + | + | + |
| 309-94 | + | + | + | + |
| 309-95 | + | + | + | + |
| 309-96 | + | + | + | + |
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| 309-98 | + | + | + | + |
| 309-99 | + | + | + | + |
| 309-100 | + | + | + | + |
| 309-101 | + | + | + | + |
| 309-102 | + | + | + | + |
| 309-103 | + | + | + | + |
| 309-104 | + | + | + | + |
| 309-105 | + | + | + | + |
| 309-106 | + | + | + | + |
| 309-107 | + | + | + | + |
| 309-108 | + | + | + | + |
| 309-109 | + | + | + | + |
| 309-110 | + | + | + | + |
| 309-111 | + | + | + | + |
| 309-112 | + | + | + | + |
| 309-113 | + | + | + | + |
| 309-114 | + | + | + | + |
| 309-115 | + | + | + | + |
| 309-116 | + | + | + | + |
| 309-117 | + | + | + | + |
| 309-118 | + | + | + | + |
| 309-119 | + | + | + | + |
| 309-120 | + | + | + | + |
| 309-121 | + | + | + | + |
| 309-122 | + | + | + | + |
| 309-123 | + | + | + | + |
| 309-124 | + | + | + | + |
| 309-125 | + | + | + | + |
| 309-126 | + | + | + | + |
| 309-127 | + | + | + | + |
| 309-128 | + | + | + | + |
| 309-129 | + | + | + | + |
| 309-130 | + | + | + | + |
| 309-131 | + | + | + | + |
| 309-132 | + | + | + | + |
| 309-133 | + | + | + | + |
| 309-134 | + | + | + | + |
| 309-135 | + | + | + | + |
| 309-136 | + | + | + | + |
| 309-137 | + | + | + | + |
| 309-138 | + | + | + | + |
| 309-139 | + | + | + | + |
| 309-140 | + | + | + | + |
| 309-141 | + | + | + | + |
| 309-142 | + | + | + | + |
| 309-143 | + | + | + | + |
| 309-144 | + | + | + | + |
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| 309-146 | + | + | + | + |
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| 309-149 | + | + | + | + |
| 309-150 | + | + | + | + |
| 309-151 | + | + | + | + |
| 309-152 | + | + | + | + |
| 309-153 | + | + | + | + |
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| 309-156 | + | + | + | + |
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| 309-160 | + | + | + | + |
| 309-161 | + | + | + | + |
| 309-162 | + | + | + | + |
| 309-163 | + | + | + | + |
| 309-164 | + | + | + | + |
| 309-165 | + | + | + | + |
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| 309-167 | + | + | + | + |
| 309-168 | + | + | + | + |
| 309-169 | + | + | + | + |
| 309-170 | + | + | + | + |
| 309-171 | + | + | + | + |
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| 309-181 | + | + | + | + |
| 309-182 | + | + | + | + |
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| 309-184 | + | + | + | + |
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| 309-212 | + | + | + | + |
| 309-213 | + | + | + | + |
| 309-214 | + | + | + | + |
| 309-215 | + | + | + | + |
| 309-216 | + | + | + | + |
| 309-217 | + | + | + | + |
| 309-218 | + | + | + | + |
| 309-219 | + | + | + | + |
| 309-220 | + | + | + | + |
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| 309-302 | + | + | + | + |
| 309-303 | + | + | + | + |
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| 309-338 | + | + | + | + |
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| 309-340 | + | + | + | + |
| 309-341 | + | + | + | + |
| 309-342 | + | + | + | + |
| 309-343 | + | + | + | + |
| 309-344 | + | + | + | + |
| 309-345 | + | + | + | + |
| 309-346 | + | + | + | + |
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| 309-348 | + | + | + | + |
| 309-349 | + | + | + | + |
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| 309-351 | + | + | + | + |
| 309-352 | + | + | + | + |
| 309-353 | + | + | + | + |
| 309-354 | + | + | + | + |
| 309-355 | + | + | + | + |
| 309-356 | + | + | + | + |
| 309-357 | + | + | + | + |
| 309-358 | | | | |



b. via "Record Home Page"

Patient ID 309-47
Arm 1: Neuropathies

| Data Collection Instrument | Enrolment and first visit | Visit-unrelated | + Add new Visit |
|---|---------------------------|-----------------|-----------------|
| Consent | | | |
| Baseline | | | |
| Visit Data | | | |
| Genetic Diagnosis: Changes in nuclear DNA | | | |
| Negative Genetic Tests (only when no genetic diagnosis) | | | |
| Medication | | | |
| WHODAS 2.0 12-item (survey) | | | |
| PGI-C (only available if date of birth filled in Baseline) (survey) | | | |
| End of Data Collection | | | |
| Delete all data on event: | | | |

Repeating Instruments

Consent
Enrolment and first visit (Arm 1: Neuropathies)
(1)

| | | |
|---|--|------------|
| 1 | | 2023-08-23 |
|---|--|------------|

+ Add new

c. in the affected forms of the relevant records

Patient ID 309-47
To rename the record, see the record action drop-down at top of the [Record Home Page](#).

The entry of data is only possible with the written informed consent of the patient.

Patient ID
309-47

Please document the Patient ID within your local patient file, otherwise you may not be able to identify the patient at a later point.
No personally identifying information about the patient is stored in this registry.

CONSENT

Date of consent
yyyy-mm-dd Today Y-M-D
* must provide value



6.2.2 Updating data for registered patients via CSV-upload

Assume we want to update data of the existing patient “John Doe” in the EURO-NMD Registry from the consent-example above. Just for an example, we will update their data of consent from the currently stored value 23.08.2023 to 30.08.2023. We can achieve that by using a CSV like:

```
record_id,redcap_event_name,redcap_repeat_instrument,redcap_repeat_instance,date_of_consent,consent_complete
309-47,enrolment_and_firs_arm_1,consent,1,2023-08-30,0
```

Note that this time we need to first find the assigned REDCap-“Patient ID” (record_id) for “John Doe” from the local systems at the treating health care provider and then use the REDCap-“Patient ID” (here: 309-47) in the CSV used for data import into the registry.

To update data by importing this CSV into the EURO-NMD Registry, you have to:

1. Open “Data Import Tool” from the “Applications”-section of the left menu.
2. Provide the following settings for updating existing patient-records in the registry:

- a. Record format: Rows
 - b. Format for date and datetime values: MM/DD/YYYY or YYYY-MM-DD
 - c. Allow blank values to overwrite existing saved values? No, ignore blank values in the file (default)
 - d. **Name the imported records automatically (force record auto-numbering): No, use the record name provided**
 - e. Choose the delimiter for the uploaded file: Comma (,)
3. Attach the CSV-file to the upload under “Upload you CSV file”
 4. Click on “Upload File”
 5. Now, you should see a page to review the provided data, again with a “Data Display Table”:

| KEY for Data Display Table below | |
|----------------------------------|---------------------------------|
| Black text = | New Data |
| Gray text = | Existing data (will not change) |
| (Red text) = | Data that will be overwritten |

| DATA DISPLAY TABLE | | | | | |
|-----------------------------|--------------------------|------------------------|--------------------------|----------------------------|------------------|
| record_id | redcap_repeat_instrument | redcap_repeat_instance | redcap_event_name | date_of_consent | consent_complete |
| 309-47 (existing record) | consent | 1 | enrolment_and_firs_arm_1 | 2023-08-30 (2023-08-23) | 0 |

6. Thoroughly check the imported data in the overview.
 - a. If you spot problems in the data import, cancel the import by clicking on “Cancel”: Then edit the provided CSV as needed and try again.
 - b. If all data in the overview is correct then click on “Import Data”. In this example, we see that the previous value 2023-08-23 for date_of_consent will be overwritten with the new date 2023-08-30 as intended. We can proceed and import data.



6.2.3 Required data format for fields with ontology-validation

In the EURO-NMD Registry, several fields include ontology-validation (from here on simplified "ontology-field"). An ontology is a formal description of knowledge as a set of concepts within a domain and the relationships between them. For example, the Orphanet Rare Disease Ontology (ORDO) is a vocabulary for rare diseases, the Human Phenotype Ontology (HPO) is a standardized vocabulary of phenotypic abnormalities encountered in human disease.

You can quickly identify the fields with ontology-validation by opening the REDCap-internal Codebook of the EURO-NMD Registry and then using your browsers search-function (usually [CTRL]+[F]) and search for "BIOPORTAL":

| | | | |
|----|---|---|---|
| 38 | [diagnosis_rd_orpha] Show the field ONLY if: [diagnosis_rd] = 'diagnosed' | Diagnosis of the neuromuscular disease (ORPHAcode) <i>Diagnosis retained by the specialised centre (Element 6.1. in the Set of common data elements for Rare Diseases Registration (link))</i> | text, Required BIOPORTAL:ORDO BIOPORTAL:ORDO |
|----|---|---|---|

There, you can also see the required prefix for the values in ontology-fields. In the shown example, we see that the field *diagnosis_rd_orpha* requires the prefix "ORDO". That means, values in this field must have the format "ORPHA:<code(integer)>", for example ORPHA:273 for Steinert myotonic dystrophy.

During manual data entry, fields with ontology validation allow a user to simply start typing keywords and the system searches for matching terms in the ontology that the field is validated against and display them as a dropdown-list that the user then selects from:

In contrast to manual data entry, where it is impossible for users to enter data into an ontology field that is not permitted in the vocabulary, there is no such strict validation for CSV-based data import. During CSV-based data import, it is unfortunately not technically impossible for invalid values to be written to ontology fields (tested under REDCap version 13.7.23).

For ontology-fields, please check particularly carefully that only correctly formatted values are actually imported. To make sure that you are using the correct formatting, you can, for example...

- first enter some data manually in the field in REDCap, then export the data (raw data, not labels) and check in the export what the correct formatting is
- during the import, check the listed values for ontology-fields displayed under "warnings" and only import data if you are confident that the values are valid
- after a data import, randomly open some of the affected forms in REDCap and check whether the label for the imported code can be correctly resolved in the ontology field.

Here is an example of what it looks like for a valid code:

Here is an example of what it looks like for an invalid code:



- on the page “Data Quality”, execute rules to identify invalid codes in ontology-fields, for example rule 1:

| | | | | |
|---|--|---|---|---------|
| 1 | Value for ORPHAcode for diagnosis must have the format: "ORPHA:", for example for example ORPHA:273 for Steinert myotonic dystrophy. | !isblankormissingcode([diagnosis_rd_orpha]) AND (!starts_with([diagnosis_rd_orpha], 'ORPHA:') OR !isinteger(right([diagnosis_rd_orpha], (length([diagnosis_rd_orpha])-6)))) | ✓ | Execute |
|---|--|---|---|---------|

6.2.4 Adding multiple follow-ups at once

Assume we want to add the most important symptom for enrolment and multiple follow-ups of an existing patient at once.

```
record_id,redcap_event_name,redcap_repeat_instance,date_of_visit,pheno_yes_1,pheno_hpo_1,visit_data_complete
309-47,enrolment_and_firs_arm_1,,2023-08-30,1,HP:0009005,1
309-47,visit_arm_1,1,2023-11-11,1,HP:0020061,1
309-47,visit_arm_1,2,2024-01-30,1,HP:0001260,1
309-47,visit_arm_1,3,2024-01-30,1,HP:0001324,1
```

The value for redcap_repeat_instance in the first line must remain empty because the event “Enrolment and first visit” is not repeatable. On the other hand, we can add as many instances of the “Visit”-event as needed by simply counting redcap_repeat_instance up, starting at 1 for the first follow up, 2 for the second follow up etc.

When you follow the same procedure as described in “6.2.2 Updating data for registered patients via CSV-upload” with this CSV, REDCap will display some additional warnings along with the data display table because we are uploading data for a field with ontology-validation (see also chapter 6.2.3):

Warnings were detected in the file that was uploaded.
There are 4 warnings (shown in orange) in this dataset. Please review the warnings below before importing the data.

| Record | Field Name | Value | Error Message |
|--------|-------------|------------|---|
| 309-47 | pheno_hpo_1 | HP:0009005 | This field is an ontology auto-suggest field, and while it is allowable to import data for this field, it is generally advised against since this value might not display correctly if viewed afterward on a report or in the data entry interface. |
| 309-47 | pheno_hpo_1 | HP:0020061 | This field is an ontology auto-suggest field, and while it is allowable to import data for this field, it is generally advised against since this value might not display correctly if viewed afterward on a report or in the data entry interface. |
| 309-47 | pheno_hpo_1 | HP:0001260 | This field is an ontology auto-suggest field, and while it is allowable to import data for this field, it is generally advised against since this value might not display correctly if viewed afterward on a report or in the data entry interface. |
| 309-47 | pheno_hpo_1 | HP:0001324 | This field is an ontology auto-suggest field, and while it is allowable to import data for this field, it is generally advised against since this value might not display correctly if viewed afterward on a report or in the data entry interface. |

Instructions for Data Review

The data you uploaded from the file is displayed in the Data Display Table below. Please inspect it carefully to ensure that it is all correct. After reviewing it, click the 'Import Data' button at the bottom of this page to import this data into the project.

KEY for Data Display Table below

Black text = New Data
Gray text = Existing data (will not change)
(Red text) = Data that will be overwritten

| record_id | redcap_repeat_instrument | redcap_repeat_instance | redcap_event_name | date_of_visit | pheno_yes_1 | pheno_hpo_1 | visit_data_complete |
|-----------------------------|--------------------------|------------------------|--------------------------|---------------|-------------|-------------|---------------------|
| 309-47 (existing record) | | | enrolment_and_firs_arm_1 | 2023-08-30 | 1 | HP:0009005 | 1 |
| 309-47 (existing record) | | 1 | visit_arm_1 | 2023-11-11 | 1 | HP:0020061 | 1 |
| 309-47 (existing record) | | 2 | visit_arm_1 | 2024-01-30 | 1 | HP:0001260 | 1 |
| 309-47 (existing record) | | 3 | visit_arm_1 | 2024-01-30 | 1 | HP:0001324 | 1 |

When we then ignore this warning and click on “Import Data” on the bottom of the page, we see that the import is still successfully executed and that “1 record was created or modified during the import.”



The Record Home Page of record_id 309-47 now looks like this:

Patient ID **309-47**
Arm 1: Neuropathies — TestCenter2

| Data Collection Instrument | Enrolment and first visit | Visit-unrelated | Visit 2023-11-11 (#1) | 2024-01-30 (#2) | 2024-01-30 (#3) |
|---|------------------------------------|-----------------------|----------------------------------|----------------------------------|----------------------------------|
| Consent | <input checked="" type="radio"/> + | | | | |
| Baseline | <input type="radio"/> | | | | |
| Visit Data | <input checked="" type="radio"/> | | <input checked="" type="radio"/> | <input checked="" type="radio"/> | <input checked="" type="radio"/> |
| Genetic Diagnosis: Changes in nuclear DNA | | <input type="radio"/> | | | |
| Negative Genetic Tests (only when no genetic diagnosis) | | <input type="radio"/> | | | |
| Medication | | <input type="radio"/> | | | |
| WHODAS 2.0 12-item (survey) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| PGI-C (only available if date of birth filled in Baseline) (survey) | <input type="radio"/> | | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| End of Data Collection | | <input type="radio"/> | | | |
| Delete all data on event: | × | | × | × | × |

And when we open the individual “Visit Data”-forms, we see that the symptoms encoded with the human phenotype ontology are correctly resolved and displayed, for example under enrolment:

Element 6.3. in the Set of common data elements for Rare Diseases Registration ([link](#))

| No | Provide phenotype | Phenotype (HPO) |
|----|--|---|
| 1 | <input checked="" type="radio"/> Yes <input type="radio"/> No | <input type="text" value="Weakness of the intrinsic hand muscles"/> HP:0009005 |



6.2.5 Troubleshooting: Handling invalid data with the data import tool

Some error messages during data import cause the import to be blocked. In this case, all errors in the CSV used must first be corrected.

Example: datatype *number* for field *body_height_cm*

Description of *body_height_cm* in the Codebook:

| Instrument: Visit Data (visit_data) | | | |
|-------------------------------------|---|------------------------|---|
| 106 | [body_height_cm_known] | Body Height (cm) known | radio yes Yes no No Field Annotation: @DEFAULT = 'yes' |
| 107 | [body_height_cm] Show the field ONLY if: [body_height_cm_known] = 'yes' | Body Height (cm) | text (number), Required |

Example-CSV with errors:

```
record_id,redcap_event_name,redcap_repeat_instance,body_height_cm_known,body_height_cm
1,enrolment_and_firs_arm_1,,yes,ffff,1
2,enrolment_and_firs_arm_1,,yes,"180,1",1
3,enrolment_and_firs_arm_1,,yes,147.6,1
```

Settings for the data import:

Record format: The file to be uploaded has its records stored as separate

Format for date and datetime values:

Allow blank values to overwrite existing saved values?

Name the imported records automatically (force record auto-numbering)

Choose the delimiter for the uploaded file:

This CSV includes 2 unacceptable values for *body_height_cm*:

| ERROR DISPLAY TABLE | | | |
|---------------------|----------------|-------|---|
| Record | Field Name | Value | Error Message |
| 479 | body_height_cm | ffff | The value you provided could not be validated because it does not follow the expected format. Please try again. |
| 480 | body_height_cm | 180,1 | The value you provided could not be validated because it does not follow the expected format. Please try again. |

No data (also not the correctly formatted data from the line for record_id = 3) can be imported until these problems have been resolved in the CSV.

Example-CSV with errors resolved:

```
record_id,redcap_event_name,redcap_repeat_instance,body_height_cm_known,body_height_cm
1,enrolment_and_firs_arm_1,,yes,176,1
2,enrolment_and_firs_arm_1,,yes,180.1,1
3,enrolment_and_firs_arm_1,,yes,147.6,1
```

Expect no errors:

| DATA DISPLAY TABLE | | | |
|-------------------------------|--------------------------|----------------------|----------------|
| record_id | redcap_event_name | body_height_cm_known | body_height_cm |
| 482 (tentative new record) | enrolment_and_firs_arm_1 | yes | 176 |
| 483 (tentative new record) | enrolment_and_firs_arm_1 | yes | 180.1 |
| 484 (tentative new record) | enrolment_and_firs_arm_1 | yes | 147.6 |

Note: This example has been greatly simplified for better readability. In practice, of course, it makes sense to import many more missing fields at the same time and ensure that at least the mandatory fields in the instrument in question are all included in the import CSV.



7 History of changes

| Version | Section | Description of changes |
|----------------|----------------|-------------------------------|
| 1 | all | First public version |