



USER GUIDE DATA MANAGEMENT

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1 DATA MANAGEMENT

To access and manage patient data, log in to the registry as a user with data access permissions, e.g. 'DataEntry+' (Figure 1). Different roles confer different levels of access (e.g. entering data, exporting data, adding patients), so you should make sure to have the right set of permissions required for your task. Management of users and the respective roles and permissions is performed by (local) registry administrators; please contact them with any access-related issues.

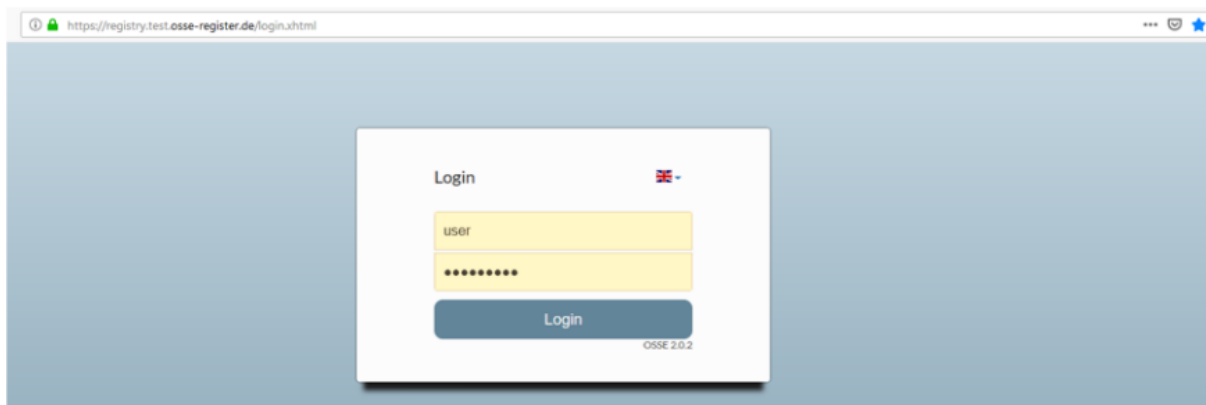


Figure 1

1.1 USER PROFILE

The user profile can be accessed by clicking on the user name in the top right and selecting 'Edit Profile'. It allows users to select a default role and change their own password (Figure 2). Since the password is set by a (local) registry administrator when setting up a user account, it is recommended that users change their password following the first login.

For a user with several roles, e.g. data entry and administration or data entry for different locations, the current role can be changed in the drop-down menu at the top of the page.

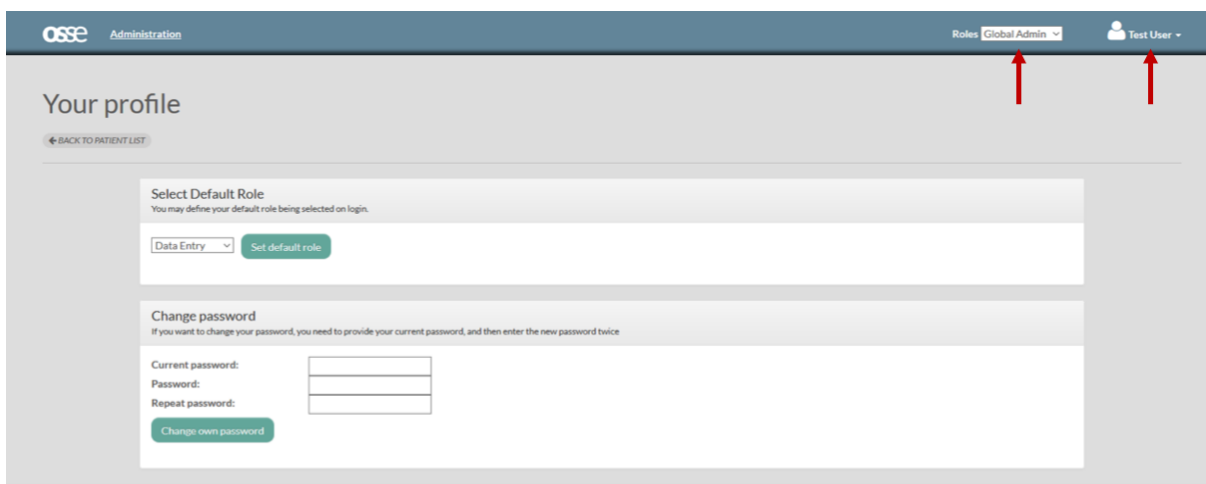


Figure 2

1.2 PATIENT LIST

All patients recorded in the registry are displayed in the patient list (Figure 3). The first column contains either only the PID or the name and the PID of a patient, depending on the location and permission set of your role. The patient's date of birth is displayed in the second column (if available) while the third column contains the location where the patient was added. The icons in the last column allow you to edit, export or delete the patient and his data.

The columns can be sorted in ascending or descending order by either clicking on the column name or the arrows in the top right corner of the title row. You can search the patient list via the text box ('Search'), e.g. for a specific location or patient name, and filter for patients with open or reported forms ('Filter'). From any of the following screens you can return to the patient list by clicking 'Overview' in the top left corner.

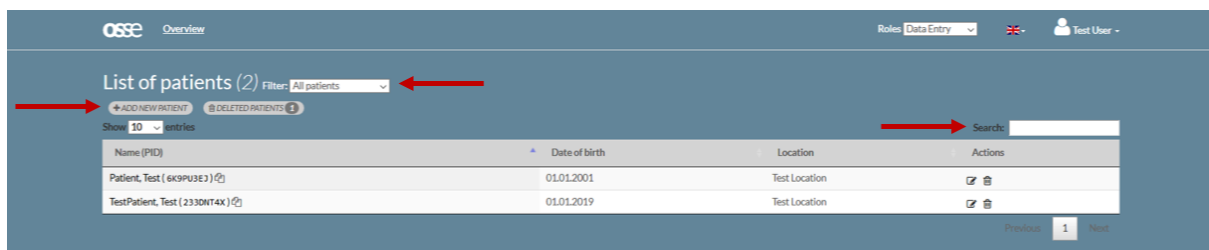


Figure 3

1.2.1 ADDING NEW PATIENTS

To add a new patient to the registry, click the '+ADD NEW PATIENT' button to access the user interface of the Mainzelliste pseudonymization software. Enter the patient's first name(s), name, birth name (optional, if different from last name), birthdate, zip code (optional) and city (optional) and click 'Add patient' (Figure 4). A pseudonym will now be requested for this patient. If the patient already exists in the Mainzelliste, the existing pseudonym (PID) is returned, otherwise a new one will be created. It is not possible to create a new pseudonym for a patient with personal data (name, date of birth) identical to a patient already stored in the Mainzelliste.

The screenshot shows the 'New patient' form. At the top, there's a header with 'OSSE' and 'New patient'. Below this, there's a section titled 'Personal data'. Inside this section, there's a paragraph explaining that the application produces a patient identifier (PID) based on the entered personal data. Below this paragraph are four bullet points providing instructions: 1. If first or last name consist of multiple components, enter all components, separated by spaces or hyphens. 2. In case of compound names, check if they are written as one word (like 'Annalena') or separated ('Anna-Lena'). 3. Enter the birth name only if it differs from the last name. 4. The fields marked with '*' are mandatory. The form fields are: 'First name(s):' with value 'Test', 'Last name:' with value 'Patient', 'Birth name:' with value 'New', 'Date of birth:' with a date picker set to '01 January 2001', and 'City of residence: (Postal code / City)' with two empty input fields. At the bottom of the form, there are two buttons: 'Add patient' (green) and 'Cancel' (red).

Figure 4

Sometimes a patient with similar but not exactly matching data is found in the database. In that case you will be asked to either provide additional information if possible via the 'Correct data' button or confirm the details you entered via the 'Confirm data' button (Figure 5).

OSSE

Uncertain case

Personal data

An existing patient with similar data was found in the database. However, the similarity is not sufficient to match the entered data to the existing case.

Please check if your data is correct and if you can provide additional fields.

- Click "Correct data" to go back to the entry form in order to make corrections or to provide additional data.
- If you can assure that the data is correct and the patient has not been entered before, click on "Confirm data" to add a new patient with the entered data.
- If you are confident that this patient already exists in the database, please contact the database administrator in order to resolve the conflict manually.

First name(s): *

Last name: *

Birth name: * (if different)

Date of birth:

City of residence:

(Postal code / City)

Figure 5

After requesting a pseudonym for your patient, make sure to accept the verification dialog by clicking 'Save' or 'Save and another one' to add the patient into your OSSE registry (Figure 6).

OSSE Overview Roles: Data Entry Test User

Patient, Test (6K9PU3EJ)

*01.01.2001

You have added the patient Patient, Test (*01.01.2001) to your Mainzliste. With this, the identifying attributes of your patient were pseudo-anonymised and the personal identifier (6K9PU3EJ) was created.

To finalize adding the patient into your registry, press save. In case you do not want to add this patient into your registry, press 'cancel'.

Figure 6

1.2.2 CHANGING PATIENT DETAILS

To modify a patient's personal data, click the corresponding edit symbol in the 'Actions' column of the patient list. Please be aware that you are making changes to patient data stored in the Mainzliste pseudonymization server, where patients for all locations of the registry are recorded. Any modifications made by you might therefore have side effects for other locations. In theory it is possible (but not recommended) to retrospectively modify a patient's name or date of birth without changing the pseudonym. This might result in two patients with identical personal data (name, date of birth) but different pseudonyms.

1.3 PATIENT DATA FORMS

To open the dataset of a patient, click on the patient name or the PID in the first column of the patient list. This will open a new page with two sections: a patient form containing all basic data forms and a carousel of episodes on top of the screen (Figure 7). Each episode represents a point in time or short period of time where longitudinal data is collected. You can navigate through the episodes, which are sorted chronologically, using the arrows on the left and right. Clicking on the date will open an episode and display a list of longitudinal data forms for this episode. To return to the start of the patient data set click on the patient name (or PID) on top of the screen.

The screenshot shows the patient data forms interface. At the top, the patient name and pseudonym with date of birth are displayed: "TestPatient, Test (233DNT4X)" and "01.01.2019". Below this is the "Episodes (2)" section, which includes a "NEW EPISODE" button and a carousel of episodes. The episodes are listed with dates: "25/03/2019 Episode 1" and "25/06/2019 Episode 2". The main section is the "Patient Form", which contains a "Family History" section. The "Family History" section is divided into "Mother" and "Father" sections. Each section contains fields for "Year of birth", "Ethnicity", "Chronic kidney disease?", and "Other chronic disease?". The "Chronic kidney disease?" field has radio buttons for "Yes", "No", and "Unknown". The "Other chronic disease?" field has a text input. The "Known consanguinity of parents?" field has radio buttons for "Yes", "No", and "Unknown". The "Degree of consanguinity" field has a dropdown menu. At the bottom of the form are "Save changes" and "Cancel" buttons. Annotations with red arrows point to various elements: "patient name / pseudonym + date of birth" points to the top header; "episode carousel (longitudinal data forms)" points to the episode carousel; "list of basic data forms" points to the left sidebar; "form name / description" points to the "Family History" section header; and "data entry fields" points to the form fields.

Figure 7

1.3.1 MANAGING EPISODES

To create a new episode, click the '+ NEW EPISODE' button, enter the date and optionally a short text and click 'Save' (Figure 8). The episode is then added to the carousel on top of the screen and a list of empty longitudinal data forms will be displayed (Figure 9).

You have the option of importing one or all longitudinal data forms from the previous episode, i.e. transferring previously recorded data into the current episode. Click the corresponding button above the episode carousel and confirm that you want to proceed with the import; this will overwrite any existing data in the form(s). You will still be able to enter new data or change imported data of course. To delete an episode from the patient dataset, click the 'DELETE CURRENT EPISODE' button and confirm that you want to delete the selected episode in the dialogue.

OSSE Overview Roles: Data Entry Test User

Patient, Test (6K9PU3EJ)
*01.01.2001

Date of Episode * 02/10/2019

Optional text

Save Cancel

Figure 8

OSSE Overview Roles: Data Entry Test User

Patient, Test (6K9PU3EJ)
*01.01.2001

Episodes (2) +NEW EPISODE -EDIT CURRENT EPISODE -DELETE CURRENT EPISODE -TRANSFER THIS FORM'S DATA FROM LAST EPISODE -TRANSFER ALL FORMS' DATA FROM LAST EPISODE

02/09/2019 02/10/2019

Episode: 02/10/2019

General Examination
General Examination Version: 2

Height

Weight

Recent symptoms

- ☐ Muscle cramps
- ☐ Nausea
- ☐ Vomiting
- ☐ Hypertension
- ☐ Fatigue
- ☐ Loss of appetite
- ☐ Chest pain
- ☐ Shortness of breath

Laboratory analysis

Date	Analyte	Measurement	Unit of measurement	Action
No entries				

Add new entry

Figure 9

1.3.2 ENTERING PATIENT MEDICAL DATA

To enter medical data for a patient, select a form (its status will change from 'unused' to 'open') and fill in the appropriate values (Figure 10). After clicking the button 'Save changes', a pop up ('Saving succeeded') will confirm that the data you entered has been saved (Figure 11). Please be aware that any data you entered will be lost if you leave the page without successfully saving the changes made to the form. A warning message will appear when trying to leave a form with unsaved changes.

Figure 10

Figure 11

Some notes on entering or changing patient data:

- Hovering the mouse cursor over a field or item will display a tooltip with a short definition or further instructions for completing this field.
- If applicable make sure to enter values corresponding to the indicated unit of measurement (e.g. 'cm' or 'mmol/l').
- Mandatory fields are marked with an asterisk (*) and are highlighted red if you try and save changes without entering data. Please note that none of your data can be saved until all mandatory fields are completed.
- Some fields only allow entering values from a specified range or data type (e.g. whole numbers or decimal numbers). If the data entered exceeds the range or does not correspond to the specified data type, these will be highlighted red and display a short error message when trying to save the form. Please note that none of your data can be saved until any faulty entries are corrected.
- In some cases, additional items or questions will appear depending on the information you provide, e.g. 'How many children?' if you checked 'yes' when queried whether the patient has any children.
- In other cases, e.g. for a list of current medication, you might have to generate a table, providing the information indicated in the headers for each entry. After clicking the 'Add new entry' button, a row of data input fields becomes available for each column of the table. Existing rows can be deleted from the table using the bin icon on the right.