



# ESID Online Registry

## User Manual

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## 1 Introduction

Welcome to the ESID Online Registry for Primary Immunodeficiencies. This web-based database system allows you to enter and access patient data in a secure decentralized way through the internet via your own browser. This manual includes a detailed guide to the documentation process.

All pages in the system include detailed descriptions (tool tips and other explanations). Therefore, most of the features should be self-explanatory. With this manual, we mainly want to describe the general documentation process and those features which are probably not completely “intuitive”.

The ESID Registry project is managed at the Center for Chronic Immunodeficiency at University Medical Center Freiburg.

**Current project leader:** Prof. Stephan Ehl, Head of the ESID Registry Working Party


**Project coordination:** Dr. Gerhard Kindle, Benjamin Gathmann

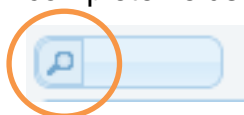
## 2 Working with the Database System

Before we start this tour, we would like to remind you that you are working with real patient data. Therefore, please observe the following user principles:

- every user of the system (= every user name) corresponds to one person only.
- never log into the system with someone else's user name.
- close the session by logging out after finishing your work.
- keep your password in a secure place
- use a secure password
- change your password regularly

## 2.1 General principles

- Please make a selection **for every field** – this is necessary in all forms of the Registry (if not stated otherwise).
- To save the data, you **must** click the “Create” or “Save” button below every form.
- Some centres use a **personalized version** of the system, i.e. they can work with patient names. The additional features of this version are described in 2.9
- Buttons with a question mark:  contain definitions for all fields where necessary.
- The system contains “classic” drop down menus as well as searchable auto-complete fields. The latter are marked by a magnifier like this:

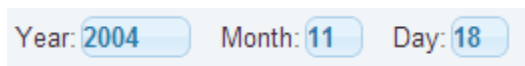


To use this type of field

1. Enter two or more characters
  2. Wait until a list of matching entries is displayed and select one of these
- Date fields:
    - Fields that ask for a complete date contain a date picker that appears upon selection of the field:



- Date fields that are split into three fields:



Here, it is possible to leave month and day open. Please only enter the date as precisely as known. Do not use dates like 2000-1-1 or 2000-15-6 to signal that month and day are unknown. This only leads to flaws in data quality.

- Some fields only appear after you have selected a specific field, e.g.:

Familial Case  Yes  No  Unknown

Familial Case  Yes  No  Unknown

Index patient

Index patient is the patient's

- If you have not completed a field or entered inconsistent data, messages are displayed on top of the page:

**⚠ The field Sex cannot be empty. Please enter or select a value.**  
**⚠ Please enter a value for the field Country of Birth**

**Create Patient**

Patient Consent  Full consent  Research only  Not applicable (deceased)

Date of birth  Year: 2000 Month:

Country of Birth

Sex  Male  Female  Unknown

## 2.2 Accessing the system

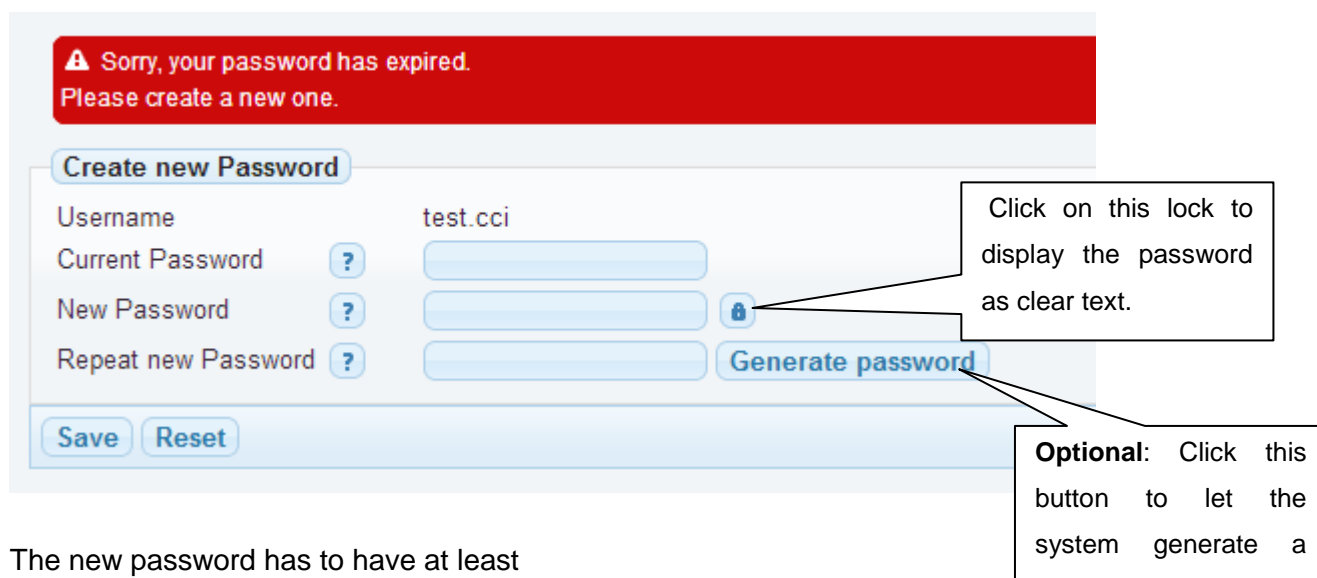
Enter the following URL in your browser:

<https://cci-a1.ukl.uni-freiburg.de/EERS>



Enter the login credentials you received from the ESID Registry team.

When you log in for the first time, you will be asked to change your password:



The new password has to have at least

- 1 upper case letter,
- 1 lower case letter,
- 1 digit,
- 1 special character of this list: +\_.,:;=?!#

and has to be between 6 and 16 characters long.

In case you have trouble logging in, you find our contact details in the HELP menu (top right).

## 2.3 The main page (patient list)

After logging in, the system shows a list of your patients. This is the view that the system also returns to if you click “Select patient” in the top left corner.

The following columns are displayed:

- ESID ID: The unique patient ID
- Year of Birth
- Living Status (alive, deceased...)
- Sex
- PID Diagnosis
- Gene
- Last date of docu: The date of the last documentation timepoint
- Date of last news: The date that the most recent documentation is based on (as entered in form “Current status”)
- Level 1 Complete: “Yes” if level 1 was completed at the last date of docu

Each column can be used to filter the list, e.g.:

ESID ID	Year of Birth	Living Status	Sex	PID Diagnosis	Gene	Last Date Of Docu	Date of Last News	Level 1 Complete
30000	2000	All	All	CVID		2014-06-04		Yes
30926	2003	Deceased		SCID	IL7Ralpha	2014-05-13	2014-05-01	Yes
30927	2004	Lost to follow-up		Shwachman-Diamond-syndr	SBDS	2014-04-30	2012-04-16	No
30928	1998	Discharged after complete recovery	Female	Agammaglobulinemia		2014-04-30	2014-04-22	No
30930	2000	Alive	Female	Combined ID	PNP	2014-04-29	2014-04-01	Yes
30931	2006	Alive	Male	Congenital neutropenia		2014-05-02	2012-06-11	No
30933	2000	Alive	Female	CVID		2014-04-29	2014-04-08	No
30934	1996	Alive	Male	Unclassified IDs		2014-05-05		No
30936	2002	Alive	Male	Combined ID	LIG4	2014-05-05	2014-05-01	Yes
30938	2002	Alive	Female	CVID		2014-05-05	2014-02-05	No
30940	2003	Alive	Female	CVID		2014-06-04	2014-04-01	No
30944	2001	Alive	Male	ALPS		2014-04-29	2014-04-01	No
30952	1994	Alive	Male	CSR / HGM (Hyper-IgM)	UNG	2014-05-02	2014-05-01	No
30955	2001	Alive	Female	Shwachman-Diamond-syndr	SBDS	2014-05-12	2014-05-01	No
30956	1999	Alive	Female	Shwachman-Diamond-syndr	SBDS	2014-05-12		No

The list can be exported in different formats using the buttons displayed below the list

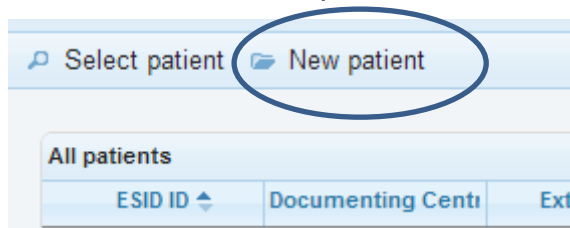


By default, the list shows 15 entries per page. You can set a personal default value of up to 100 entries in your account settings (2.10).

For users who enter data for more than one center, an additional column “Documenting Centre” is visible in the patient list.

## 2.4 Adding a new patient

In order to add a new patient, select „New patient“ on the top left of the page:



The following page shows up. Please enter the details for the patient.

Explanations for the fields are available via the “?” buttons.

 A screenshot of the 'Create Patient' form. The form contains several fields with radio button options:
 

- Patient Consent:  Full consent,  Research only,  Not applicable (deceased)
- Date of birth: Year: , Month:
- Country of Birth:
- Sex:  Female,  Male,  Unknown
- Country of current residence:
- Death before initial registration:  (highlighted by a callout box)
- Familial Case:  No,  Yes,  Unknown
- Twin:  No,  Yes: identical,  Yes: non-identical,  Yes, but heredity unknown,  Unknown
- Consanguinity of parents:  No,  Yes,  Probable,  Unknown
- Documenting Centre:
- Test Centre:

 At the bottom of the form are 'Create' and 'Reset' buttons. A callout box points to the 'Death before initial registration' field with the text: 'Please only report deceased patients if this is required by your centre.'

After you have successfully created the patient entry, the standard patient tabs are shown (see 2.6)

## 2.5 Verifying an imported patient

In order to verify an existing entry, click on the entry in the list. You are then asked to confirm that the patient is still alive (This does not apply for deceased patient entries transferred from another registry).

 A screenshot of a dialog box titled 'Confirm Patient Living Status'. It contains a 'Please select' label and the question 'Is this patient still alive?' with three radio button options: 'Yes', 'No', and 'Unknown'. The 'Yes' option is selected. At the bottom of the dialog box are 'OK' and 'Cancel verification process' buttons.

If the patient was still alive at the last time you heard of him, select "Yes". You can enter the time point of last news later on in the "Current status" form (2.6.2). This



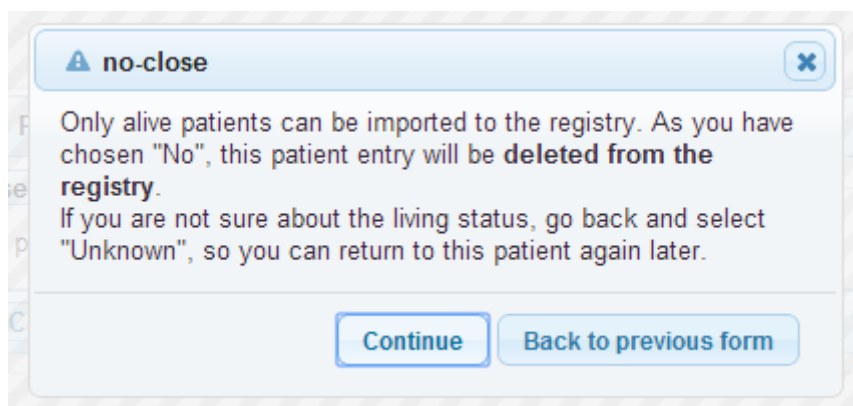
also means that: If the last time you saw him was a long time ago (e.g. two or three years), but your center still follows this patient, select "Yes".

If the last time you saw him was a long time ago (e.g. more than three years) and your center does NOT follow him anymore, select "No". This is because you should only register patients currently followed by your center.

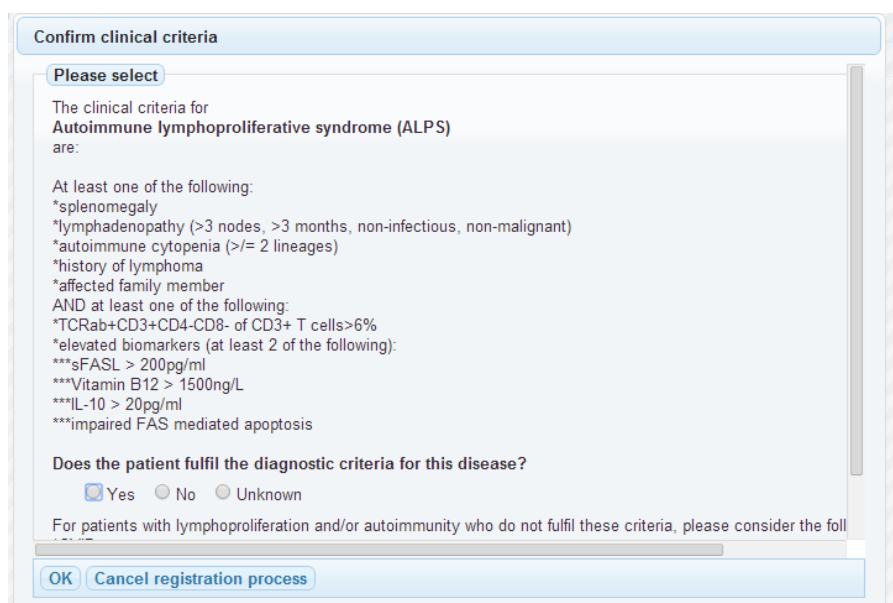
If you know that the patient is now followed by another center, and this is an ESID Registry Documenting Center, please send us an email with the patient ID. We can arrange a transfer of this entry to the other center then.

If you select "No", the entry will be deleted from the system. This is because the system is not intended for retrospective documentation of deceased patients.

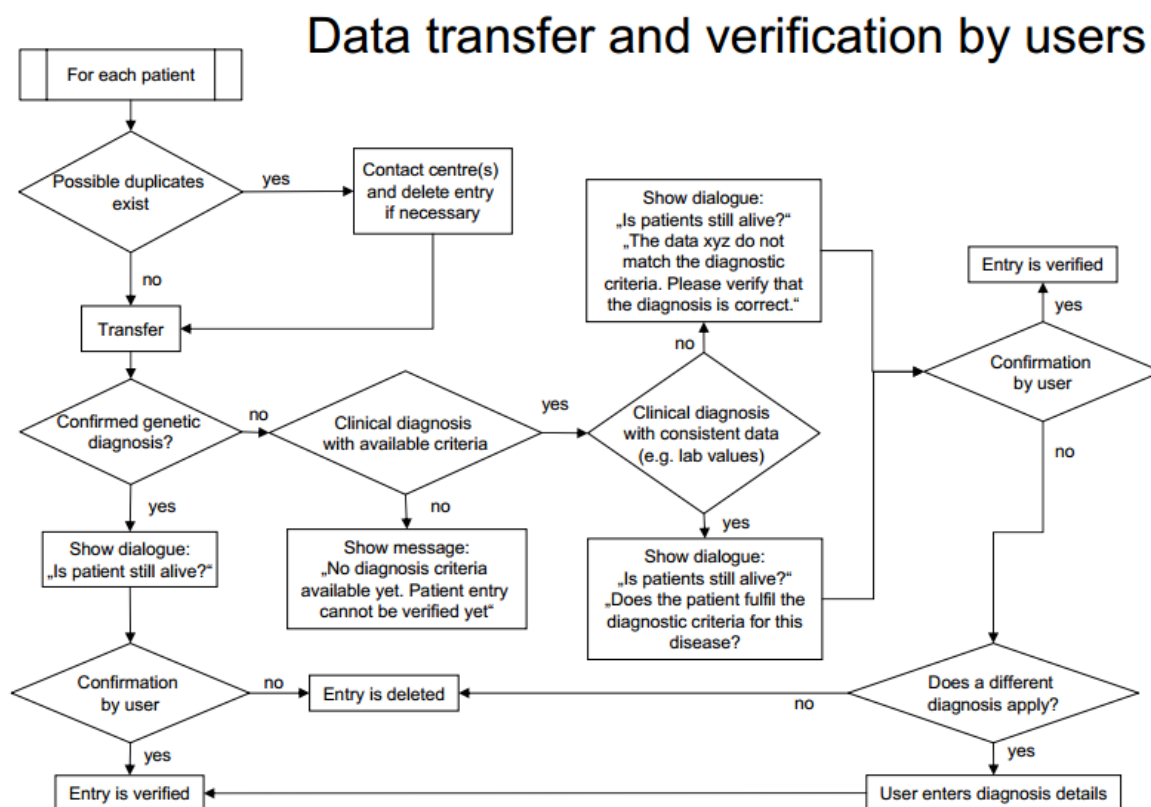
The system asks you for confirmation before the entry is deleted:



Next, depending on the type of diagnosis, the system asks you to confirm or change the diagnosis, e.g.:



The underlying process is depicted here:



If you have successfully verified the entry, the patient tabs are shown for further editing (see 2.6).

ESID ID: 30940 - Diagnosis: CVID - Year of birth: 2003 - Age: 11 / Doc. date: 2014-06-04

Information: Patient entry verified. Date of first documentation set to: 2014-06-04

**Edit Patient**

Patient Consent  Full consent  Research only  Not applicable (deceased)

Date of birth  Year  Month

Country of Birth

Sex  Female  Male  Unknown

Country of current residence

Familial Case  No  Yes  Unknown

Twin  No  Yes: identical  Yes: non-identical  Yes, but heredity unknown  Unknown

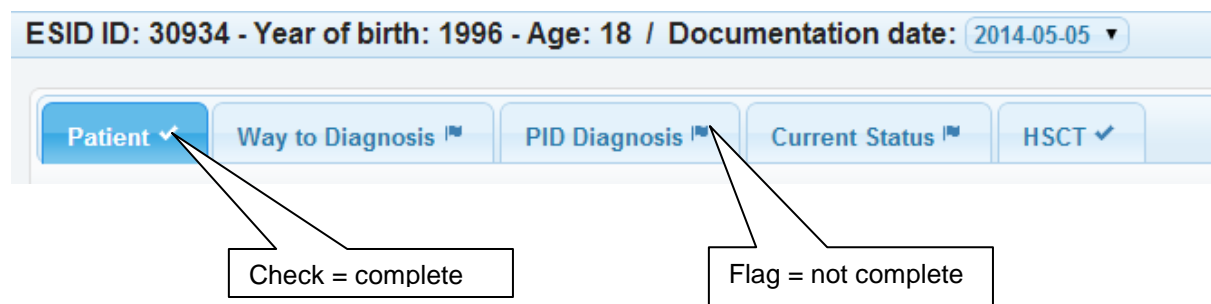
Consanguinity of parents  No  Yes  Probable  Unknown

Documenting Centre

## 2.6 The Patient tabs

The patient tabs are the standard view for a patient.

There is a header row that shows the patient's unique ID, the year of birth and current age, as well as the currently selected Documentation date:



The tabs themselves carry checks and flags that signal whether the form has already been completed.

If you are editing a patient that has been imported, some forms may already contain data, but the forms are not marked as complete, because selections are missing for some items.

In order to complete a patient, please select every tab marked by a flag and enter the necessary data.

The Documentation date which is shown on the top right cannot be edited manually. It is the time point when the patient was created (or verified, see 2.5) and inserted automatically by the system.

Some of the tabs (forms) are described in detail in the following chapters.

## 2.6.1 PID Diagnosis

In the PID Diagnosis form, it is possible to enter a diagnosis with known or unknown genetic defect:

- Known genetic defect:

You can either select a clinical diagnosis (“Current PID diagnosis”), and the possible genes for this diagnosis are displayed:

OR you can first enter the gene and then select a suitable PID diagnosis:

- Unknown genetic defect:

Use the “Current PID Diagnosis” field to select a PID diagnosis. Next, you will be asked to confirm the clinical diagnosis criteria (as described in the verification process (2.5)).

### Genetic laboratories:

There is a field that asks for the name of the “Lab that performed the genetic analysis”. You can select one of the names from the list and see the details for the lab by clicking on the question mark if you want to make sure that this entry is correct:

Lab that performed the genetic analysis ? Paris, CEDI ? Name of lab unknown

Sequencing method x ?

Reason for genetic analysis x ?

Save Reset Add new entry

**Lab-Details**

**Name:** Paris, CEDI  
**Full Name:** Study center of primary immunodeficiencies (Centre d'étude des déficits immunitaires (CEDI))  
**Contact Person:** Capucine Picard  
**Contact Email:** capucine.picard@inserm.fr  
**Country:** France

OK

## 2.6.2 Current status

Patient, Way to Diagnosis and PID Diagnosis only have to be completed once (at the first documentation = baseline documentation). The Current Status form has to be completed at every documentation timepoint.

This is what the Current Status form looks like at baseline:

Please note the following:

- You must enter a “date of last visit” of the patient at your centre or the “date of last news” from the patient. This is important to know which timepoint the reported data refers to.
- If you select “Ig replacement”, an additional tab (form) appears.
- The same is valid for HSCT and Gene therapy.

Additional forms

### 2.6.3 Ig replacement

The form for immunoglobulin replacement includes many automatic checks as well as calculations in order to ensure that data is entered complete and correct.

Some of these features are described here:

- Only appropriate routes are shown for each brand:

Current brand name   Unknown  
 Current route of administration  Intravenous  Subcutaneous  Intramuscular

Current brand name  **Hizentra / CSL Behring**  
 Current route of administration  Subcutaneous  Intramuscular

Current brand name  **Endobulin / Grifols**  
 Current route of administration  Intravenous

- Automatic calculation of dose:

Enter mg/kg OR absolute dose OR BOTH

This read-only value is calculated from dose & interval & weight

The interval can be entered in two different formats – please select one of these for each entry:

every   weeks  days

time(s) per  week  month  year

Patient's current weight  kg  Unknown  
 Current dose  mg/kg body weight Dose per month:   
 Current dose (total amount)   grams  milliliters  
 Dose unknown   
 Interval for this dose  Select interval-type first:  every x weeks or days  x time(s) per week, month or year  
 Interval unknown

Example of automatic calculation:

The weight is needed to calculate the mg/kg dose

Patient's current weight	<input type="text" value=""/>	kg	<input type="checkbox"/> Unknown
Current dose	<input type="text" value=""/>	mg/kg body weight	Dose per month: <input type="text" value=""/>
Current dose (total amount)	<input type="text" value="10.3"/>	<input checked="" type="radio"/> grams	<input type="radio"/> milliliters
Dose unknown	<input type="checkbox"/>		
Interval for this dose	Select interval-type first: <input checked="" type="radio"/> every x weeks or days		
	<input type="text" value="5"/>	<input checked="" type="radio"/> weeks	<input type="radio"/> days

Patient's current weight	<input type="text" value="35"/>	kg	<input type="checkbox"/> Unknown
Current dose	<input type="text" value="294"/>	mg/kg body weight	Dose per month: <input type="text" value="235"/>
Current dose (total amount)	<input type="text" value="10.3"/>	<input checked="" type="radio"/> grams	<input type="radio"/> milliliters

These two values are calculated and stored by the system

If you enter BOTH mg/kg dose and absolute dose, the system calculates whether the two match. If not, a dialog box is shown as follows:

<input type="text" value="300"/>	mg/kg body
<input type="text" value="100"/>	grams
every <input type="text" value="5"/>	weeks
<input type="checkbox"/>	
<input type="text" value="35"/>	kg <input type="checkbox"/> Unknown

⚠ no-close
✕

The absolute dose does not match the dose in mg/kg. The calculated value is 143 mg/kg

Take calculated and save
Take yours and save
Return to form

If you enter the dose in milliliters, the brand name is needed for the calculation, because each brand has a specific IgG concentration:

Current brand name	<input type="text" value="Subcuvia / Baxter"/>	<input type="checkbox"/> Unknown
Current route of administration	<input type="radio"/> Subcutaneous <input type="radio"/> Intramuscular <input type="radio"/> Unknown	
Current place of administration	<input type="radio"/> Home <input type="radio"/> Hospital <input type="radio"/> Hospital: inpatient <input type="radio"/> Hospital: outpatient	
Patient's current weight	<input type="text" value="35"/>	kg <input type="checkbox"/> Unknown
Current dose	<input type="text" value="294"/>	mg/kg body weight    Dose per month: <input type="text" value="365"/>
Current dose (total amount)	<input type="text" value="100"/>	<input type="radio"/> grams <input checked="" type="radio"/> milliliters

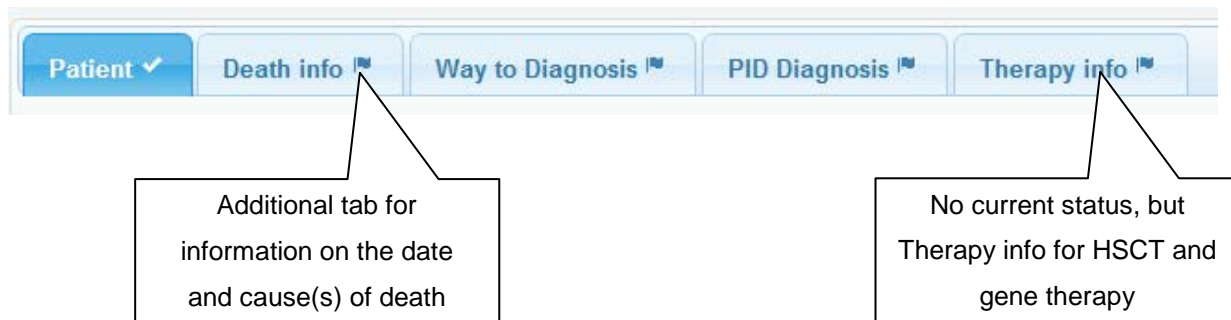


## 2.7 Deceased patients

If you are

- a) working on an imported entry of a deceased patient or
- b) have selected “Death before initial registration” for a new patient,

the Patient tabs look slightly different:



Please note that no follow-ups can be entered for deceased patients. Previous entries for Ig replacement remain stored. Data on HSCT and gene therapy can still be entered.

The “Death info” tab contains an additional section for ICD10 codes. This section is – in contrast to all other items in the Registry – optional. It was added because some centres need this categorization for internal purposes.

**Create Death info**

**Date of death** ?

Year  Month  Day

Date of death unknown

**Main cause(s) of death** ?

<input type="checkbox"/> Septic shock	<input type="checkbox"/> Heart failure	<input type="checkbox"/> Respiratory failure	<input type="checkbox"/> Liver failure
<input type="checkbox"/> Renal failure	<input type="checkbox"/> Multiple organ failure	<input type="checkbox"/> Haemorrhage	<input type="checkbox"/> Thrombosis
<input type="checkbox"/> Neurological complications	<input type="checkbox"/> Surgical complications	<input type="checkbox"/> Drug toxicity	
<input type="checkbox"/> Relapse of malignancy	<input type="checkbox"/> Veno-occlusive disorder		
<input type="checkbox"/> Graft-versus-host Disease	<input type="checkbox"/> Rejection/Poor graft function	<input type="checkbox"/> Post-transplant lymphoproliferative disorder	
<input type="checkbox"/> Other main factor			
<input type="checkbox"/> Main death factor unknown			

**Underlying morbid setting(s) associated with mortality** ?

Infection

Malignancy

? Immune dysregulation

Transplantation-related cause

Other underlying cause:

Underlying cause unknown

**ICD-10 categorisation (optional)** ?

Code ?

Text ?

## 2.8 Follow-up documentation

If you have completed a documentation timepoint for a patient, it is possible to add a follow-up documentation. Follow-ups for each patient will be requested by the system once per year, but you can enter as many follow-ups as you like.

Please note though that only one documentation timepoint is possible per day. This also implies that you cannot enter baseline data and follow-up data on the same day, because the documentation date is automatically generated and stored by the system.

This is an example for a complete documentation timepoint:

- All tabs have a check sign
- “+ Follow up” is displayed next to the current documentation date



ESID ID: 30936 - Year of birth: 2002 - Age: 12 / Documentation date: 2014-04-29 Follow up

Patient ✓ Way to Diagnosis ✓ PID Diagnosis ✓ Current Status ✓ Ig-Replacement ✓ HSCT ✓ Gene therapy ✓

The following dialog box is shown:

**Add Follow Up** ✕

Add follow up documentation for this patient?

OK Cancel

Next, the patient tabs are shown, and the Current Status form is selected:

Patient ✓ Way to Diagnosis ✓ PID Diagnosis ✓ **Current Status** HSCT ✓ Gene therapy ✓

**Create Current Status**

Date of last news from patient ?   No news from patient since last documentation

This is the date of the ?  last clinical visit  last news (phone, letter etc.)  unknown

Current status ?  Alive  Deceased  Lost to follow-up  Discharged after complete recovery

Changes to diagnosis ?  No Change  PID diagnosis has changed  No PID after all

Current Ig replacement ?  Yes  No  Unknown

HSCT ?  Yes  No  Unknown SCETIDE ID ?  EBMT

Gene therapy ?  Yes  No  Unknown

Save Reset

As you can see, all other tabs do NOT have to be documented again, except for Ig replacement. Only the following items require documentation:

Date of last news from patient ?

(or alternatively the date of last news from the patient)

Current status (the previous entry is selected):

Alive  Deceased  Lost to follow-up  Discharged after complete recovery

Changes to diagnosis (No change is pre-selected)

No Change  PID diagnosis has changed  No PID after all

Therapy items:

Current Ig replacement ?  Yes  No  Unknown

Haematopoietic stem cell transplantation (HSCT) ?  Yes  No  Unknown

Gene therapy ?  Yes  No  Unknown

You need to change HSCT and gene therapy only if it was “No” or “Unknown” previously, because the previous selection is already displayed (so “Yes” remains “Yes” and does not have to be selected again at every documentation).

Please also note that all HSCT and gene therapies are only entered once and can be edited at every documentation timepoint.

### 2.8.1 Changing the PID diagnosis

If you have found a genetic mutation in your patient, you can simply enter this into the PID diagnosis. However, if the **clinical diagnosis (“PID Diagnosis”)** has **changed**, this has to be documented as a new diagnosis entry, in order to preserve the previous data:

The screenshot shows the 'Current Pid Diagnosis' form. It has tabs for 'Patient', 'Way to Diagnosis', 'PID Diagnosis', and 'Current'. The 'Current Pid Diagnosis' section contains the following fields:

- Current PID diagnosis: ? [Unclassified synd]
- Affected gene: ?
- Additional genes: ?
- Genetic tests performed?: x ? [Yes, but no mutatio]
- Lab that performed the genetic analysis: ? [Newcastle]

At the bottom, there are buttons for 'Save', 'Reset', and 'Add new entry'. The 'Add new entry' button is circled in orange.

The screenshot shows the 'New Pid Diagnosis' form. It has a 'Create PID Diagnosis' section with the following fields:

- Current PID diagnosis: ? [Search]
- Affected gene: ? [Search Pid by Gene]
- Additional genes: ?
- Genetic tests performed?: x ? [Yes, but no mutation found, Not genetically tested, History of genetic tests unknown]

At the bottom, there are buttons for 'Save' and 'Reset'.

Previous diagnosis entries are displayed as a list below the current diagnosis:

**Current Pid Diagnosis**

Current PID diagnosis

Affected gene

Additional genes

Date of genetic diagnosis Year:  Month:  Day:   Date unknown

Reason for genetic analysis  Analysis following clinical diagnosis  Family screening  Prenatal diagnosis  
 Diagnosis by neonatal screening  Unknown

Sequencing method  Gene sequencing  Whole exome/genome sequencing  Unknown

Lab that performed the genetic analysis   Name of lab unknown

---

**Pid Diagnosis-List of former diagnoses**

Current PID diagnosis	Affected gene	Additional genes	Diagnosis valid from	Diagnosis valid until
Unclassified syndromic immunodeficiencies			2014-04-28	2014-06-04

Page 1 of 1 | View 1 - 1 of 1

Export:

Documentation timepoint when the former diagnosis was entered

Documentation timepoint when a new diagnosis was entered instead

## 2.8.2 Loading previous data for Ig replacement

In order to minimize the documentation burden, you can load the Ig replacement data from the previous documentation timepoint into the form:

The screenshot shows the 'Create Ig-Replacement' form with the following fields and options:

- Current brand name: [?]
- Current route of administration:  Subcut
- Current place of administration: [?],  Home
- Patient's current weight: [?] kg
- Current dose: [?]
- Current dose (total amount): [x] [?]
- Dose unknown: [?],
- Interval for this dose: [?], Select inte
- Interval unknown: [?],
- Current side effects: [?],  Yes

At the bottom, there are three buttons: 'Save', 'Reset', and 'Load previous data'. The 'Load previous data' button is circled in orange.



The screenshot shows the 'Create Ig-Replacement' form after data has been loaded from a previous date. A yellow banner at the top indicates 'Data loaded from date: 2014-08-13'. The form fields are populated with data from that date:

- Current brand name: [?], Flebogamma 10% / Grifols,  Unknown
- Current route of administration:  Intravenous,  Unknown
- Current place of administration: [?],  Home,  Hospital,  Hospital: inpatient,  Hospital: out
- Patient's current weight: [?], 55 kg,  Unknown
- Current dose: [?], 91 mg/kg body weight, Dose per month: 1274 [?]
- Current dose (total amount): [x] [?], 5,  grams,  milliliters
- Dose unknown: [?],
- Interval for this dose: [?], Select interval-type first:  every x weeks or days,  x time(s)
- every 2,  weeks,  days

Please also note that the date of the (very) first Ig replacement is only requested at the baseline documentation:

The screenshot shows the 'Date of first Ig replacement' field with the following options:

- Date of first Ig replacement: [?], Year: [ ], Month: [ ], Day: [ ],  Date unknown

## 2.9 Personalized version

If your centre uses the personalized version, i.e. patient names are included, there are additional features.

### 2.9.1 Patient list with names

In the patient list, you can display patients' names. You can enable this feature by clicking on "Show patient names":



The screenshot shows a patient list interface. At the top, there is a button labeled "Show patient names" with a blue arrow pointing to it. Below this is a table with the following columns: ESID ID, Documenting Centre, Year of Birth, Living Status, and a fifth column for gender. The table contains several rows of patient data.

ESID ID	Documenting Centre	Year of Birth	Living Status	
<input type="text"/> x	Test <input type="text"/> x	<input type="text"/> x	All <input type="text"/> x	All
30000	Test Centre	2000	Alive	Female
30926	Test Centre	2003	Alive	Female
30927	Test Centre	2004	Alive	Male
30928	Test Centre	1998	Alive	Female
30930	Test Centre	2000	Alive	Female
30931	Test Centre	2006	Alive	Male
30932	Test Centre	2000	Alive	Female

Please note that if your centre has a large number of patients, it may take up to 15 seconds to load the patients' names because the personal patient data is stored on another server and loaded into the page.

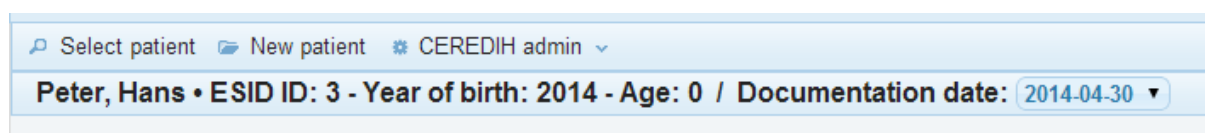
Therefore, you can switch between "Show patient names" and "Hide patient names" as you like. You can also set a default value for this feature in the "Account settings" (2.7).

You can also **download** the patient list with names, using the button below the list:

Export: [CSV](#)

Currently, only CSV format is available. Depending on your browser, you will need to save and rename the downloaded file to a .csv file. In order to open it with Excel, please use the Excel text import function.

The patient's name is always displayed on top of the page, independent of the patient list setting:



The screenshot shows a header bar for a patient record. It includes navigation links for "Select patient", "New patient", and "CEREDIH admin". The patient's name and details are displayed as "Peter, Hans • ESID ID: 3 - Year of birth: 2014 - Age: 0 / Documentation date: 2014-04-30".

Select patient	New patient	CEREDIH admin
Peter, Hans • ESID ID: 3 - Year of birth: 2014 - Age: 0 / Documentation date: 2014-04-30		

## 2.9.2 Create a new patient

If you create a new patient, the system redirects you to the other server in order to enter the patient name etc. (screenshots next page).

This other server has two purposes:

1. It stores the patient name, complete date of birth and place of residence so this data can be loaded into the ESID Registry
2. It performs a so called "record linkage" and thereby prevents reporting of duplicate entries.

For the second task, it is important that you really enter as many details as possible, and not only the patient names.



### Generate patient ID

**Information**

This application provides an identification code (ID). It uses the personal data entered in the following fields to find possible matches in the current list of entries. After you have submitted the data below, your web browser will return to the main server pages. In case of a direct match, you will be redirected to the matching entry, in case this patient belongs to your centre.

- Please enter all known first names, separated by blanks
- Make sure to enter connecting characters correctly (e.g. "Annalena" or "Anna-Lena").
- Please enter the maiden name if different from the current family name.
- The fields marked with a \* are mandatory
- Currently, the following (non-ASCII) special characters are supported: ` ç í à á â é ê ë ò ó ñ ã Ä Ö Ü ß

The following data is only stored on the Patient List server which is separated physically from the Patient Data server, and managed by different personnel.

First name(s) :  \*

Family name :  \*

Maiden name :  (if different from current family name)

Date of birth :  \*

Place of residence :   (ZIP code / town)

Please also enter zip code and place of residence as well as maiden name (if available) in order to make your entry duplicate-proof.

Contact: ESID Online Registry coordination, CCI, University Medical Center Freiburg, Tel. +49 761 270



## Result

An ID for this patient has been generated and sent to the Patient Data server

### Provided data (which is stored on Patient List server)

Name : Hans  
 Family name : Peter  
 Maiden name :  
 Date of birth : 01.April 2014  
 ZIP code and town of residence : 79100 Freiburg

[Return to Patient Data server](#)

### Patients resembling this entry

nachname [MUELLER, , ]  
 geburtsmonat 2  
 geburtsname [ , ]  
 vorname [HANS, , ]  
 geburtsjahr 2014  
 geburtstag 1  
 ort  
 plz  
 Matching weight: 0.7041653761736741

Click here to continue the documentation of this patient.

If the patient is a duplicate, the following page is shown. Please note that if the **existing entry belongs to your centre**, you are redirected to this entry afterwards.

If the entry belongs to another centre, you are redirected to your patient list.

## Patient exists!

There is a direct match for this entry in the Patient List (100% certainty).  
 If you click on the button below, you will be redirected to the Patient Data server.

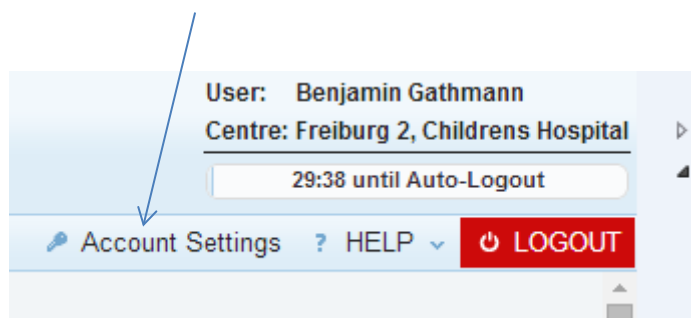
### Provided data

Name : Hans  
 Family name : Peter  
 Maiden name :  
 Date of birth : 01.April 2014  
 ZIP code and town of residence :

[Return to Patient Data server](#)

## 2.10 Account settings

You can edit your account and change your password by clicking the link on the top right of the screen:



The 'Edit user data' form contains the following fields and options:

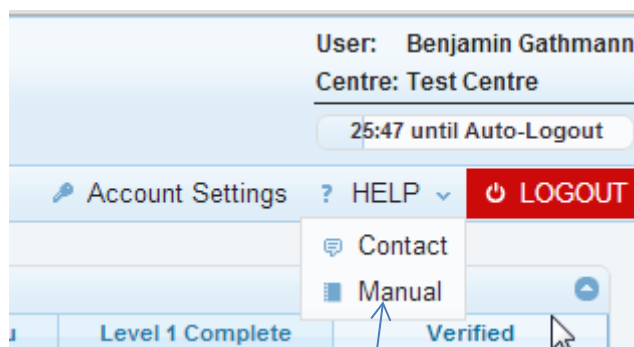
- User name: b.gath.admin
- Change Password: [Change Password](#)
- Centre: Test Centre
- Title: [Mr.](#)
- First name: [Test](#)
- Last name: [Testman](#)
- Gender (sex):  Female  Male  Unknown
- Profession:
- Email: [test@test.de](#)
- Alternative email address:
- Telephone:
- Fax number:
- Address: [Test Street 1](#)
- Postal code: [12345](#)
- Town: [Test City](#)
- Country of living: [Germany](#)
- Affiliation (for publications):
- Display names in patient list:  [?](#)
- Patient List size: [15](#) [?](#)
- Language: [English](#) [?](#)
- App Theme: [Theme: cupertino](#)
- Display animation in info dialogs:  [?](#)

Three callout boxes provide additional information:

- Top Callout:** These contact details are used by the ESID Registry team to contact you e.g. send you a new password, invite you to join a study etc.
- Middle Callout:** If you use the personalized version, you can set the default patient list behavior here.
- Bottom Callout:** Define a standard number of patient entries per page in the patient list.

### 3 Contacting the Registry administrator

For contacting us, you can either send an email or call us (details see below) – or you can use the contact form inside the Registry which is available in the “HELP” menu:



As you can see, this manual itself is also available in the “HELP” section.

Use the contact-form below or write an email directly to: [esid.registry@kenes.com](mailto:esid.registry@kenes.com)

**Get in contact**

Topic

Subject

Your message

Upload attachment (max. 2MB)

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You can reach us also by telephone: +49 (0)761 270-78171

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or by FAX: +49 (0)761 270-36960

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Contact address: Benjamin Gathmann  
Centrum Chronische Immundefizienz - CCI  
Engesserstr. 4  
D-79108 Freiburg  
Germany

#### Contact details:

University Medical Center Freiburg  
Center for Chronic Immunodeficiency (CCI)  
Engesser Str. 4  
79108 Freiburg; Germany  
Tel.: +49-761-270-78171  
Email: [esid.registry@kenes.com](mailto:esid.registry@kenes.com)

## **4 Registry FAQ**

This manual does not answer all possible questions.

A good starting point for questions not answered here are our FAQ which you may find here:

[http://esid.org/content/download/13670/386342/file/Registry\\_FAQ.pdf](http://esid.org/content/download/13670/386342/file/Registry_FAQ.pdf)