

## ESID Registry



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## 1. Transferred patients

### a. What can I do if the system tells me “Sorry, there are no criteria available for disease XYZ yet”?

We are currently working on providing clinical criteria for all diseases in the ESID Registry, starting with the most frequent ones like IgG subclass deficiency. Until these are available, you have two options:

- Postpone the verification until the criteria are available
- Select the diagnosis suggested by the system (e.g. “Unclassified hypogammaglobulinaemia”) for this patient and change it once the criteria are available.

### b. I have an entry that has been genetically defined in the meantime (e.g. STAT1). The system asks me to change the diagnosis because no clinical criteria are available (e.g. for CMC). What shall I do?

In this case, select “Yes” to “Would you like to modify the diagnosis?”. In the next form, enter the same diagnosis as before + the gene. The system will let you save this as a valid diagnosis.

### c. Where has “Other hypogammaglobulinaemias” gone?

“Other hypogammas” is now part of “Unclassified antibody deficiency”. Please read the clinical disease criteria for further information.

### d. Why can I not enter a follow-up for a transferred patient right away?

When you verify an existing (imported) patient (Patient is alive + Diagnosis is correct), a documentation date is set by the system.

This is then the "Baseline date" for this patient. This means that the data is treated as if the patient is being entered for the very first time in the Registry, even if he had already been registered in the old system.

So all the data that you enter then is actually the current data. You don't have to enter it as a follow-up.

In the "Current status" form, you can enter a "date of last news" manually, because this date can be different from the current date (e.g. patient was last seen five months ago).

### e. What do I select if a transferred patient is lost to follow-up?

When you select a patient for the first time in the new Registry, you are asked whether he/she is still alive.

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.

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. Current status and follow-up

**f. If I add a new date of documentation, does the new “date of last news” replace the one previously recorded?**

No, the new "date of last news" will not replace the one previously recorded. The form "Current status" holds some fields which always stay the same (e.g. "HSCT" - if it is "Yes", it remains "Yes" for all follow-ups), but e.g. "Date of last news" and "Ig replacement" have to be entered again on every follow-up.

**g. In which situation do I have the possibility to see the option "add follow-up" ?**

This option does not appear if the “documentation date” is today. Adding a follow-up only makes sense if there are news on the patient since the last documentation (which is unlikely to happen until tomorrow).

**h. How often should I enter a follow-up documentation?**

So a follow-up should usually be filled in once per year.

## 2. Patient names

**a. I have a patient where the name is missing (e.g. because it was not entered in the old Registry). How do I add the name?**

For the patients that you have already entered before, you can add the names following the instructions given in the user manual, Section 2.9.4.

## 3. Genetics

**a. Can I enter the name of the gene, even if the patient has not ticked the “genetics” option in the patient consent form?**

Yes, to our best knowledge this does not violate ethical rules, because the name of the gene is an integral part of the PID diagnosis.

**b. I cannot find the “genetics” option in the “Patient” form.**

This option is not available anymore, because the link to the IDBases in Finland has been terminated. Please always select “Research only”, unless the patient has ticked the “pharma” option. In this case, select “Full consent”

## 4. Ig replacement

### a. **There was an Ig replacement for a patient in the old Registry, but is not visible in the new Registry. Why not?**

We have only transferred Ig replacement entries for patients with a visit date after January 1, 2012. This is because we want to make sure to really have the current data in the ESID Registry.

## 5. Lab values

### a. **I can't put in any results of the blood test. Is it supposed to be this way?**

What you currently see in the new ESID Registry is only the level 1 dataset which is mandatory for all patients.

Blood test results as well as more detailed data on clinical presentations and treatment are part of a level 2 that will be made available soon.

We will also transfer some of the lab data from the old registry.

In any case, all the historic (old) data remains available in the old registry interface as well as the Reporting Tool or upon personal request.