Duplicate registrations
How to avoid them

Duplicate registrations occur when the patient is present more than once with different Unique Identification Codes (UIC) within the Registry database. At the moment, a double registration is entered in the database every day. This is a waste of time for the data manager doing the data entry and it is also a burden on the Registry that keeps on monitoring for duplications and investing time in cleaning the data. This is the typical example of an error that takes much longer to fix than to prevent.

We hope this document will enable you to help the Registry in preventing duplicate registrations as much as possible.

Duplicate registrations may be represented in two ways:
- the same transplant is registered twice
- the patient is given a separate UIC for each transplant

The first case is quite clearly incorrect, but the second case is also wrong. A patient is a unique individual and every treatment that a patient undergoes will determine the outcome. It is important to ensure that all the information relating to a patient is always stored under the same UIC. If this is not the case, we run the risk of researching outcome without taking into account the whole history of the patient and this can lead to erroneous results with consequences for future treatments.

The main reasons for duplication are:
1. The centre likes to keep the autografts and allografts separate, sometimes even allocating them different UPNs (Unique Patient Number in the hospital).
2. There is more than one data manager in charge of data entry
3. Centres enter the data themselves but then submit the same paper forms to the national registry or EBMT office
4. A change in personnel leads to the new staff not knowing what has or has not been entered
5. The patient was transplanted in a previous centre and the data manager has not requested access to their previous record. (See below for instructions)

The Registry has put in place error catchers that are activated during data entry to avoid patients being registered twice under separate UICs and also to avoid different patients sharing the same UPN. This error catcher will signal to the data manager that he/she is entering a UPN that has already been used, or that there is another patient with that same date of birth, asking the data manager to check it is not the same patient. Unfortunately the error catcher can only check these data against the list of patients present in the *Index screen* in *Data entry*. This means that if the *Index*

has been reduced for whatever reason, the power of the error catcher is diminished. For example, if before entering the data, the data manager filters the *Index screen* to show only patients that have undergone an allograft, the error catcher will not be able to detect whether there is a patient with the same UPN or date of birth among autografted patients.

This is also a problem with centres that have more than 2500 patients as the *Data entry Index* can only list 2500 patients at any one time.

This is what the data manager can do to avoid creating duplicates:

1. <u>Always</u> search for the date of birth of the patient you are about to enter before you begin. You can do this by
   a. sorting the patients by date of birth before you get started
   b. by doing a search for date of birth using the *Search using Patterns below* facility (See the User Guide to Promise http://www.ebmt.org/ebmt/documents/user-guide-promise for more details on how to use these facilities)
2. Do not shrink or filter the *Data entry Index* when entering new transplant registrations. This will ensure that the error catcher will have all available data to spot duplications before they happen.
3. If you are a national registry or EBMT staff, move to the corresponding CIC in addition to searching the whole registry index as indicated in point 1. above. This will ensure that all patients in that centre are actually present in the *Index,* increasing the chances that the error catcher will spot duplications before they happen. Be aware that this will not work if the transplant has been done in another centre, which is why you must always do a search for date of birth (point 1.) in the whole registry.
4. If you know that the patient has had a transplant previously, whether it is allograft or autograft, and you cannot find the record do not just create a new one:
   a. ask your colleagues/the centre if they know whether the patient was registered
   b. do a search by UPN (perhaps there is a typing mistake in the date of birth), or date of diagnosis or date of previous transplant. (Sort the centre index by date of birth; date of transplant to check for similar dates).
   c. ask the Registry helpdesk or the national registry for help
5. If you think the patient had a transplant before in another centre, request access to the data of that patient so you can add the subsequent transplant to the same patient registration. To do this, fill in the form that you can find at: http://www.ebmt.org/ebmt/documents/data-access-request-form-patient-given-previous-treatment-other-centre and submit it to the Registry office or to your national registry.
6. If there is more than one data manager doing data entry, make sure you communicate with each other and keep a common list of patients registered available for all to see.
7. The EBMT does not recommend that different UPN's be used for the same patient, but if your centre has that policy, enter all the UPN's that the patient has had allocated in the "UPN" field. For example, if the patient is allocated "345" for a first autograft, and "X231" for a second allograft, enter the UPN as "345 – X231".