Procedure for Study Groups / Societies who wish to access the EBMT Registry Database

Thank you for your interest in the EBMT Registry database. In order to make the MED-AB data available to your group, we require a signed request from each centre involved in the study group. The **request form** at the end of this document must be signed by the Principal investigator of each EBMT member centre.

Once all forms have been received at the Registry office, and if the group is new, we will issue a CIC (Centre Identity Code) and create a virtual database for your group allowing you to download or query these data at your leisure. In order to do this, you will need to assign the responsibility of accessing the EBMT Registry to a member of your team. We recommend that this person is familiar with the database and ideally they should have been trained in using the EBMT Registry database.

For your named individual(s) we require an application for data download

"ProMISe Personal Password Request Application for Data Download"

with details of the study group and your assigned CIC. The named individual(s) will have the possibility of downloading the data and the form has to be signed by the Principal Investigator of your study group.

Alternatively, if you prefer not to assign a person to download the data directly, you can ask us to provide you with a data export, however we must have a very clear description of the database items to be downloaded and for which population, since we cannot accommodate continuous requests. This service is not available if your group needs to access the data on more than one occasion.

For more information on the database content please view our web pages at:

 The Registry – Data Collection

If you have any questions on the above please contact the Registry Helpdesk

Constraints

The request will only be honoured for centres who are members of the EBMT at the time data is being accessed.

While currently this service is free, the EBMT reserves the right to charge organisations for its implementation and maintenance.

Requests are only valid for 5 years or until there is a new Principal Investigator in the centre. At this point, for the service to be continued, the request needs to be renewed.

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