



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 ProMISe system.

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

[Password Request 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.

A file with these data will be prepared and it will be your responsibility to download the file as per the instructions we will provide. If your group needs to access the data on more than one occasion, a monthly scheduled job can be prepared and again it will be your responsibility to download the file as per the instructions we will provide.

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

[Registry Structure](#)

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.



Request for centre data to be seen by other organisations

Centres must be paying members of the EBMT to make this request

(specify name of society or entity)

(specify the assigned 4 digit CIC if known)

- I request that the EBMT share MED-AB data of our centre with the above organisation
- We do not want that the EBMT share MED-AB data of our centre with the above organisation:

Period of sharing:

Until further notice*

Until: Specify date

* The request will need to be renewed every 5 years or on the appointment of a new Principal investigator at the centre.

EBMT CIC: 0 _ _ _

Name of the Principal Investigator _____

(please print)

Position _____

Signature _____

Date _____

This form must be signed by the **Principal Investigator of the centre as s/he appears in the EBMT Membership List**. If the Principal Investigator has changed, please ensure it has been updated in the EBMT membership list before submitting this form.

IMPORTANT NOTE: It is the responsibility of the centre to ensure that the permission conforms to the consent signed by the patient regarding data transmission.

Please return this form to:

fax to: +44 20 7188 8411

e-mail: registryhelpdesk@ebmt.org

scanned signed copy by post to:

EBMT Central Registry Office
4th Floor Tabard House, Talbot Yard
Guy's Hospital
Great Maze Pond
LONDON SE1 9RTUK