SUBMITTING DATA TO THE EBMT

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GETTING STARTED

How to submit your HSCT data or other Cellular therapy (CT) data to the EBMT

Our office in London deals with all data registration issues and you can contact us with any data submission queries. All data registration information and documents are located in "The Registry" section of our web site: http://www.ebmt.org

Please apply to use ProMISe to access the EBMT database through the internet for data entry.(If you belong to a National Registry that has a partnership with EBMT, please also contact them directly for further info on how to submit your data. You can view the list of affiliated registries here).

Applying to use ProMISe

ProMISe (Project Manager Internet Server) is the central data management system used by the EBMT. Users are able to enter and retrieve data directly over a secure Internet connection. All users access the same copy of the entire project, but users have the option to download their own centre database for reference purposes. The only software necessary is Internet Explorer (there is nothing to download). When online, centres can access either the complete database for an overview of all EBMT data, or their centre database, to view and enter data for their own centre.

You can access ProMISe online. It is possible to test your computer for compatibility using the Interactive Browser Configuration checker.

You may need to update your Internet browser or change your screen settings. The user manual on our Data Submission web page has further instructions

There are 2 types of ProMISe access available:

- Data Entry (one password per person - full access to your centre data including data modification). Click here to download the Data Entry application form
- Download only (one password per person - full access to your centre data excluding data modification). *This option is recommended for team members who do not enter data but wish to view their centre's data.* Click here for the Data Download application form

If you are submitting data to your national HSCT registry as well as the EBMT, do not forget to tick the box allowing your organisation to have access to your data.

The signed application form can be scanned and emailed to registryhelpdesk@ebmt.org

ProMISe Support & Training

When you apply to use ProMISe, we will send you instructions on how to access the Registry database, with the link to the user manual. A Helpdesk is available if you experience any problems or have any queries while using the database. ProMISe users receive news updates, and training sessions are organised in conjunction with EBMT meetings / national societies. Online training videos are available on https://www.ebmt.org/registry/data-submission#guides

Please email registryhelpdesk@ebmt.org for any further information.

<u>MED-AB Data Collection forms</u>

We have 2 sets of standard Data Collection Forms and you can choose to submit either MED-A, or MED-B.

The MED-A form contains the minimum essential data that must be submitted by members for every transplant performed since joining EBMT.

The MED-B forms are more detailed and provide more of the information that can be used in studies.

We request MED-A reports on day 0 (or within a week of day 0), then post transplant info at day 100, plus a follow up every year. (The MED-A form has been expanded and all MED-A items are included in the latest MED-B).

MED-A or MED-B forms are available to download online as and when required. We have also compiled a MED-AB manual, prepared by the Working Parties and revised by the Definitions Group. This document is available on the same web link and contains detailed notes and background information to help data managers who submit registrations.

A Med-A form for non HSCT Cell Therapy (and corresponding manual) is also available and can be downloaded from the same location.

Donor Outcome forms and a manual are also available here. It is already mandatory to follow up donors in some countries.

Please see over for more detailed information on the data collection forms. Should you have any queries relating to data reporting please do not hesitate to contact us.

We look forward to working with you.

The EBMT Registry Office team

<u>Data Sharing</u>

We have agreements in place with a small number of organisations so that you only have to submit the data once if you have a commitment to also send them data. Please see the link below for more info and request forms. https://www.ebmt.org/registry/data-sharing

NEW REGISTRY SYSTEM

We are currently working on the implementation of a new system, MACRO, which will replace the current ProMISe software. For more info please see our Training web page or contact registryhelpdesk@ebmt.org

MED-AB DATA COLLECTION FORMS
Please read carefully before completing the forms

The MED-AB forms contain all items requested by the Working Parties. There are 2 types of MED-A (Minimum Essential Data) form: one for hematopoietic stem cell transplantation (HSCT) and one for other types of Cell Therapy

These forms should be entered on the day of transplant (or within a week of day 0), then the remainder at 100 days post-transplant or at time of death, whichever occurs first.
Patients who die between conditioning and transplant should be reported.

It is also very important to update the follow up on a regular basis. Please see intervals below.

<u>MED-A for HSCT</u>: Download form here
This is the essential set of variables used for registration of all haematopoetic stem cell transplants performed.

We ask that you enter data on the following:

- Day 0 registration for each transplant, including the disease specific section according to the indication for transplant
- Day 100 report
- Follow up form (see intervals below)

The EBMT requests follow up at the following intervals:

- Every year if the patient was transplanted less than 10 years ago
- Every 2 years if the patient was transplanted between 10 and 20 years ago
- Every 5 years if the patient was transplanted more than 20 years ago

<u>MED-A for Cell Therapy</u>: Download form here
The Cell Therapy Registry (CTR) introduced a MED-A form for Cell Therapy in July 2007. The form was modified and greatly enhanced in 2017. This registry aims to collect data on stem cells, or progenitor cells used for treatment other than HSCT, as well as data on the clinical characteristics and outcome of the patients.

<u>MED-B for HSCT</u>: Download forms here
This larger set of specialised forms is used to provide detailed information on each transplant. It includes all the variables in the MED-A form for HSCT. For this reason, if the MED-B forms are completed <u>there is no need</u> to complete also the MED-A form.

We ask that you enter the following for each transplant (At Day 0, then at Day 100):
- Disease Specific Form corresponding to the indication for transplant; this form is preceded by a page with General Information
- Transplant Specific Form corresponding to the type of transplant performed (Autograft or Allograft)
- Disease Specific Follow Up - Annual
- if applicable, the corresponding forms in the Forms Appendix (Cord Blood, TBI etc)

<u>Form Completion Guides</u>:

Manuals and Clinical Reference Documents (including a full MED-AB manual) are also available on the MED-AB forms web page