The EBMT Registry

Data collection

EBMT
European Society for Blood and Marrow Transplantation

The new Med-A

Project background: The Registry Working Group, chaired by Per Ljungman, began this project in 2013 to revise EBMT data collection and procedures, improve data quality and adapt to a new registry system in the future.

The MED-A was becoming too limited to be used as a scientific basis for the studies that EBMT needs to carry out.

Purpose of the new Med-A

To collect baseline data to allow selection, and checking the feasibility of scientific studies both non-interventional and retrospective.

To collect detailed data on disease risk factors.

Some areas, for example detailed complication data, could still be study based (MED-B-like) for defined objectives.

New Timepoints for collecting data

In December 2015, EBMT Registry started collecting data on day 0 from all centres:-

- **Day 0 for baseline data on diagnosis and procedures**
- **Day 100 on early outcome**
- **Day 365 and yearly for follow-up**

(The rules for providing yearly, 2 yearly or 5 yearly follow up depending on how long ago the transplant was done, are still valid)

Benefits of the changes to the Med-A

- **Increase in data collected on disease**
- **Reinforces the need for close collaboration between data managers and physicians**
- **Improved scientific output of the EBMT (and Centres and National Registries)**

Drawbacks of the changes

- **Increased workload for data managers**

DATA MANAGEMENT EDUCATION SESSION

Interactive session – the changes to the Med-A

Tuesday 5 April 13.45 – 14.25

Speaker: Prof Jane Apperley Venue: Room 4F

This session will consist of a review of the new Med-A form which was implemented in December 2015 – focussing on the changes which have been introduced into the form. This will be an interactive session which includes information about the changes to key fields such as: cytogenetics, donor & donor products, cell therapy, relapse, Day 0 data entry, GvHD & the NIH criteria, molecular markers and lymphoma prognostic indexes.

We are very keen to hear any feedback regarding how you are finding the new Med-A form – the positive and the negative - and to hear about any problems you have encountered in completing it.

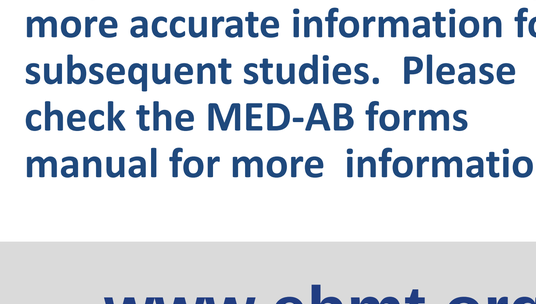
Please come along to this session and let us know what you think!

Time frame for releases

- **New MED-A paper form went online – November 2015**
- **New MED-A was implemented in Registry database (ProMISe) – December 2015**
- **MED-AB manual will be updated – work in progress. Target online date: May 2016**
- **New MED-A items will be incorporated into MED-B - work in progress. Target online date: May 2016**
- **MED-B users should continue as usual until further notice.**

Password requests

Don't forget! If you forget your password, you can now request a new one yourself on the Log-on page. Enter your user name, follow the instructions and a security code will be emailed automatically to your registered email address. Therefore, it is very important to ensure that we always have your correct email address on the system



New data items

- **More data on cytogenetics and risk factors for certain diseases**
- **More data on pre-transplant therapy (some diseases)**
- **Co-morbidity index**
- **Site specific GvHD staging**

Main structural changes

Capturing events between transplants:

Now that the new MED-A is implemented in the database, users are "forced" to enter a follow up if they attempt to enter a subsequent transplant that has not had a recent follow up. This will help to capture relapse data and other events between transplants.

Improvements to donor and product data storage :

When multiple products from the same donor are used, they are entered in the same Donor record, rather than having to create one Donor record per product as was done in the past. (Retrospective data will eventually be transferred to the correct new fields).

Lymphoma disease status at time of HSCT

This section has been changed substantially. Please read all the questions carefully before answering. The LWP believes the new implementation is simpler to fill and will convey more accurate information for subsequent studies. Please check the MED-AB forms manual for more information.