November 2015

# New MED-A coming soon

At the EBMT congress this year and in last year's newsletters we have announced that a new MED-A is under development. This is now getting very close to release.

**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 current MED-A is becoming too limited to be used as a scientific basis for the studies that EBMT needs to carry out. More information can be found in Per Ljungman's <u>presentation</u> from the last congress.

### New MED-A purpose:

European Society for Blood and

Marrow Transplantatio

- 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 reporting:

We will begin 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

#### New items:

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

#### Impacts:

- Increase in data collected on disease
- Increased workload for data managers
- Need for data manager/physician collaboration
- Improved scientific output of the EBMT (and centres)

#### Release:

- New MED-A paper form will go online
- New MED-A will be implemented in Registry database (ProMISe)
- MED-AB manual will be updated
- New MED-A items will be incorporated into MED-B. MED-B users should continue as usual until further notice.

If you have any questions please contact us on registryhelpdesk@ebmt.org

## **ProMISe Training online**

We would like to remind all users that the first training videos are now online on the EBMT Youtube channel.

The **Avoiding Data Entry Problems** and the **Data Retrieval** Training sessions have been added since the last newsletter. Below you can find a full list of the current <u>videos</u>:

MED-A Data Entry

DATA MANAGEMENT NEWS

- HLA Data Entry
- Data Entry Problems How to avoid them, how to solve them
- Data Retrieval

Each video gives comprehensive training on these subjects and you can jump to topics quickly within the videos.



We will be interested to hear your feedback to help us prepare more online training in the future. Staff in the Registry in London and the Study Office in Paris have been involved in the planning and delivery of the training.



We look forward to seeing you at the 15<sup>th</sup> Meeting of the Data Management Group in Valencia 3-6 April - **EBMT 2016** 

Please visit <u>www.ebmt2016.org</u> to register and to view the DM program which includes: Cell therapy; Conditioning; Studies and outcomes; Inherited disorders; JACIE process, Donor outcome registry; Acute Leukaemia; Cord Blood; Comorbidity index; Ex-vivo manipulation; Myeloma case studies, ProMISe data entry; retrieval, file sharing and more! More detailed information will be coming soon