DATA MANAGEMENT NEWS

May 2016

Revised MED-B

Following the introduction of the new MED-A at the end of 2015, we are getting close to our deadline for adapting the MED-B data collection to make it compatible with the new MED-A.

Draft versions of a selection of revised MED-B forms (e.g. Lymphoma; Autograft and Allograft) are available to view on our forms web page for info.

The MED-B structure will soon follow that of the new MED-A and will be divided into the following sections:

Disease specific

- MED-B Day 0: baseline data
- MED-B Day 100: best response
- MED-B Annual Follow Ups

Graft specific

- MED-B Day 0 - Autograft or Allograft
- MED-B Day 100 - Autograft or Allograft

We will make further announcements very soon to give more information when the MED-B is fully implemented in ProMISe. Further forms will be uploaded on our forms web page next week.

Further documentation:

The ProMISe User Guide has been updated in connection with the new MED-A. We will make further updates to the user guide when the new MED-B form codes are available.

In addition, we have been updating the MED-AB manual regularly. If you have any questions regarding the content of the manual please contact us.

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

Note on Lymphoma IPI scoring in MED-AB

For info, we will not be using the Age Adjusted International Prognostic Index that was originally included in the new MED-A last year. We are sorry for any inconvenience caused.

Where applicable, all patients should now be graded through the International Prognostic Index (IPI), regardless of age.

We recommend that you download forms from our web page regularly in case of minor updates.

Review of Inherited Disorders coding

We are in the process of reviewing the coding of some of these diseases with the view of reducing the number of "others" and reducing ambiguities.

This is being done in phases in collaboration with the Working Party (IEWP) and the first phase is to code those diagnoses that appear several times in "other" that can be readily identified.

Post-Congress: 15th Meeting of the Data Management Group

EBMT 2016 in Valencia was attended by around 120 Data Managers from a variety of countries. It was a very enjoyable event which offered a great opportunity for learning and collaboration.

The clinical education sessions included: Cell therapy; Conditioning for allos; Donor outcome follow up; Inherited disorders; Burning issues regarding de novo and secondary AML classification; Cord Blood; The Co-morbidity index; Ex vivo manipulation and Case Studies on evaluating response to treatment and relapse in Myeloma.

More general sessions included Performing a study; JACIE – the process explained; Optimising data collection at a BMT unit; and an interactive session regarding the Changes to the Med-A form. The ProMISe Database Training sessions were once again very well attended.

Thank you to all our presenters and to everyone who attended. Suggestions for the Data Management Programme next year are very welcome - please email: registryhelpdesk@ebmt.org. We look forward to seeing as many Data Managers as possible at EBMT 2017 in Marseille!