

DATA MANAGEMENT NEWS

December 2014

ProMISe Version 3 coming soon!

We would like to remind all users about the imminent upgrade to ProMISe 3, which is expected to take place early next year. (We will give further info on the exact date very soon).

Urgent: Current users: we would be grateful if you could <u>log in to ProMISe 2</u> and check that your correct email address is on the system. This is important for communications and ProMISe 3 password updates.



An <u>overview</u> of the ProMISe 3 Data Entry layout is available online for downloading and printing. We will be updating the <u>current User Guide</u> to ProMISe version 3, which will be online at the same location.

ProMISe 3 Data Entry & Retrieval training sessions will be available at <u>EBMT 2015</u>. More info on how to register for these sessions will follow. There will also be a exciting programme of **Educational & Scientific sessions** suitable for data management professionals of all levels and interests. We hope to see you there!

New Registry System

As you may have seen in the recent issue of <u>EBMT News</u>, the company providing technology support for our Registry Upgrade unexpectedly ceased all business operations.

Mohamad Mohty has confirmed EBMT is exploring different solutions to finalise the project and is talking to ex-Remedy Staff and to other Remedy customers that have found themselves in a similar situation. EBMT is still focused on achieving a new Registry system designed to meet future data collection and retrieval needs and, therefore, significantly improve the level of science and facilitate cooperative studies.

Contact has been made with the new owners of the company and we will keep you informed of any new developments in the coming weeks.

We will continue to work on the **Tidy Up Your Data** reports regardless of these delays and your help with this is appreciated.

Donor Identification: NMDP

The Donor ID is an important part of the donor questions in the MED-AB forms and Donor Outcome forms and is used by the Donor Registries.

Below is a request for **NMDP Donors**. The CIBMTR and NMDP have requested that the donor id given by the registry, which we store in the field "Identification of donor given by donor registry" be entered as a number only, but retaining the leading zero if it exists.

Please do not enter dashes between numbers, nor add "NMDP" or other characters to the beginning of the donor id, and do not drop leading zeros.

We provide some examples as illustration:

As it is now	It should be	
0257-8376-2	025783762	No dashes between numbers
NMDP0323- 4119-0	032341190	No additional characters, no dashes between numbers
81706343	081706343	Keep leading 0's
US033941345	033941345	No additional characters
0699-30685	069930685	No dashes between numbers

The reason for this is to facilitate the identification of the donor when EBMT forwards the data to the CIBMTR for those centres that have requested it and ensure data integrity.

We would also like to remind you that the WMDA code for the NMDP is "**USA1**" and the code for the NMDP Cord Blood Bank is "**U1CB**". Please do fill the "WMDA / BMDW code for the Donor Registry" field when entering any donor data.

Donor Identification: Cord Blood

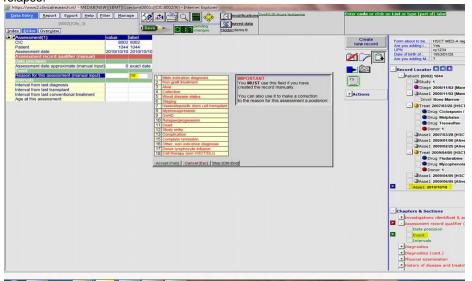
In addition to the ID for Donor Registries, we have a specific ID field for Cord Blood banks. "Identification of the CBU given by the **cord blood bank**". Note that this field is to be used exclusively for the identification of cord blood units. Please only fill for Cord Blood. The navigation in Promise should skip this field for other sources of cells. If you notice any problems please contact us.

Thank you to all users who are reporting their DONOR OUTCOME for HSCT. We will soon be collecting donor outcome for DLI and additional cell therapies as well

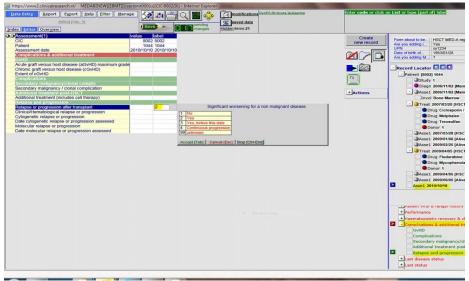
ProMISe Users: A note on manual record creation

Although we recommend following the programmed navigation for MED-AB, advanced users are sometimes creating manual records for special cases. We would like to remind users to answer the question, in addition to labeling the event for that record.

For example: If you need to create a relapse manually rather than entering a MED-A or B follow up, note that in addition to labelling the event as relapse:



The question itself "relapse/progression" also needs to be answered as "Yes" or "Continuous Progression" in addition to labelling the event:



We have been updating cases retrospectively, but from now on we would be grateful if you could fill the relapse/progression question for future cases. We will try to improve the validation in the database to prevent this question from being omitted during manual record creation. If you have any questions on the above or prefer us to modify any data please contact us.

Data collection forms

For information, we have removed the CIBMTR centre code and CIBMTR patient ID field (**CRID**) from the MED-AB forms and database. The CIBMTR provides the CRID directly to the EBMT for centres who have given permission for EBMT data to be transferred to CIBMTR

Please click <u>here</u> to download the latest data collection forms

Follow Up

We are very grateful to all centres who are reporting follow ups regularly. Requests will be sent soon for patients who have not had a follow up reported for 5 years.

> 2003/07/28 [HSCT] 2005/03/09 [Alive] 2006/06/19 [Alive]?