DATA MANAGEMENT NEWS

December 2016

Going Paper Free

As highlighted in previous news, the EBMT Registry is going paper free

For many years the EBMT has provided support to centres entering data, but now the EBMT is taking steps to go paper free in 2017. This means that data entry of standard paper forms - MED-A, MED-B, HLA and Follow Up – will no longer be offered by EBMT. By moving to the paper free data entry we expect to increase the quality of our database, encouraging a more effective process in the affected centres, as experienced by other centres across Europe that moved from submitting paper forms to entering the data themselves in the database. This decision is also in line with our commitment as EBMT to be friendly to our environment.

Most EBMT centres have already moved from paper to on-line data entry but 10% of centres remain dependent upon the Registry in London to enter their data manually.

The Registry helpdesk is always available to help your team with any questions, comments or problem regarding the Registry.

ProMISe Training Sessions

Paris, St Antoine
Monday 16 January 2017

To help with the paper free transition, a MED-A & HLA data entry training course for beginners will take place in Paris on Monday 16th January 2017. Please email registryhelpdesk@ebmt.org if you are interested in attending.

EBMT 2017, Marseille
26 – 29 March 2017

In addition, data entry training courses will be held on Monday & Tuesday during the EBMT Annual Meetings as usual. At EBMT 2017 we will cover data entry of MED-A, HLA, Cell Therapy & Donor Outcome, in addition to Advanced Data Entry & Data Retrieval

(For full details on the congress programme including educational talks for data managers, please see www.ebmt2017.org)

Code changes: Donors

Two external coding systems changed recently and are being implemented in the Registry database and the forms/manual.

Donor Registry ION Codes:

BMDW codes (unique codes representing the Donor Registries) have been replaced with ION codes.
A full conversion list is available on our web pages at http://www.ebmt.org/Contents/Data-Management/Helpdesk/Pages/Helpdesk.aspx

Most donor registries are known universally by a unique registry code beginning ION followed by 4 digits. The code can be found in ProMISe and the WMDA list is available on: https://share.wmda.info/display/WMDAREG/Database.

This list also contains some, but not all, the Cord Blood banks. Please enter this code in the form.

NMDP: Multiple Allele Codes (MAC):

For users entering HLA data in ProMISe, if you encounter ambiguous results that contain "/" e.g. 01:04/06, they should be dealt with using MACs. These were previously known as NMDP codes which could be searched for in the DNA lookup tool. This has been replaced by the new MAC lookup tool, available at https://hml.b12x.org/MacUI/

The labels named "NMDP code" will be replaced with "MAC code" in ProMISe.

An updated HLA Data Entry Guide is also available online.

Reminder: Acute Leukaemia transformed from MDS or MDS/MPN

As mentioned in previous announcements, we are following the WHO definitions of Acute leukaemia. This includes MDS or MDS/MPN transformed to AML. The WHO label for this is **AML with myelodysplasia related changes** and it includes AML where an MDS or an MDS/MPN has been diagnosed beforehand. Until a few months ago, users were asked to register these transformed cases with MDS or MDS/MPN as the Main Diagnosis - code 6.

We would like to remind users to register the main diagnosis as AML (Main diagnosis – code 1). The coding of existing registrations has been converted. Centres may be contacted where the diagnosis of existing registrations is unclear. Please see more instructions below:

1. Acute Leukaemia transformed from MDS or MDS/MPN (cont.)

Data Entry

1. User selects **Acute leukaemia** as main diagnosis
2. User selects **AML with myelodysplasia related changes** as AML subclassification
3. User is asked whether there had been a previous diagnosis of MDS or MDS/MPN.

a. If no, navigation proceeds as per AML

b. If yes, user is asked for date of the MDS or MDS/MPN

   a. User is asked for the diagnosis and stage of the MDS or MDS/MPN

   b. User is asked for the data corresponding to the form they are using (Med-A or Med-B) for the MDS or MDS/MPN diagnosis (cytogenetics and molecular markers at diagnosis, 1st line treatment up to the date of transformation)

   c. Navigation reverts back to the AML diagnosis and the standard Med-A or Med-B Day 0 is finalised.

The former sub-classification code **5** (**AML w myelodysplasia related changes (w/o previous MDS or MPS/MDS)**) has been converted to a new code: **9 "AML with myelodysplasia related changes".**

2. Old Secondary Acute Leukaemia

Until recently, the Acute leukaemia secondary to a previous treatment was being registered by asking whether the leukaemia was of "Secondary origin" once the leukaemia had been registered. According to the WHO classification, this type of leukaemia goes under the heading of **Therapy-related myeloid neoplasms**, and it is now a code within the AML classification itself.

For the data entry:

1. User selects **Acute leukaemia** as main diagnosis **(code 1)**
2. User selects **Therapy-related myeloid neoplasm (code 23)**
3. For Med-B, the navigation will follow the MDS form as usual.

EBMT Registry Staff update

Asterios Kasmiris has been working as a data manager in the EBMT Registry for 5 years. He has been appointed as Registry Helpdesk Coordinator and will be the new main point of contact on the Registry helpdesk following Pam Welson's retirement. As always, we will all be happy to help and other team members will cover the helpdesk when Asterios is not available.

In addition to their usual data management tasks, Data Managers Khrystyna Valkiv and Lucas Stolarczyk will be focusing on Data Quality and new implementations. Khrystyna has also taken on the role of coordinating the Data Management Programme at the Annual Meetings and Lucas is specialising in the data management for the new Cell Therapy implementation.


Asterios


Lucas


Khrystyna

Pam Welson retired earlier this year and is greatly missed by all her colleagues. We would like to wish her a healthy, happy retirement and all the very best for the future.