



REGISTRIES SUB COMMITTEE (RSC)

Minutes of the meeting held on 26th October 2006 in Paris

Participants: Carmen Ruiz (Chair); Sandra Allgaier; Helen Baldomero; Katerina Benesova; Nivette Bragança; Virginie Chesnel; Zina Chir; Roisin Cinneide; Sunil de Souza; Corinne Durand; Nathalie Fortin-Robertson; Shelley Hewerdine; Chantal Kenzey; Myriam Labopin; Beate Lindner; Anja Müller; Rosi Oneto; Emmanuelle Polge; Bénédicte Samey; Marjon Smeets; Keiren Towlson; Marie Trnkova, Anja van Biezen; Henk Jan van der Wijk; Marie Wilson.

1. New Members Database – Presentation - Sunil de Souza

Sunil De Souza, from the central Registry in London presented the new Members Database. This new database is linked to the Membership list on the EBMT Website.

Sunil explained why EBMT changed the Members database:

- There was a lot of Data Redundancy
- The specificity of individual membership
- A need for recurrent structural changes within the database
- A need for a better administrative use of the member's details.

With the new Members Database we now have new features that allow the following:

- A person can be a member of more than one team without repetition of their details in the database
- Designation and roles of Members are immediately reflected on EBMT Website.
- The possibility to produce yearly summaries reflecting the memberships.
- For the Office in Barcelona, yearly summaries of payments.
- For Registries, centralized contact details & registration summaries.

The new database generated a lot of interest and all participants had a lot of questions.

So who has access to the Database?

- EBMT Offices in Barcelona and London
- Barcelona Managing the Members and the Yearly Fees
- London Managing Non-Members and Promise Users Details.
- Registry Data Managers will be given access

Nathalie Fortin-Robertson, from EBMT Registry Office in London, will be responsible for updating information about non-members and Promise (Med-AB) users details.

A copy of Sunil's presentation is attached to the minutes for further reading.

2. Promise Training Update– Shelley Hewerdine

Shelley updated the group on how training for Promise users has improved in the last year.

In the past, there were a lot of Data Managers who didn't get to use Promise because of lack of training. There was no training budget then.

However, we learnt that things have greatly improved. Training is available now for Centers who wish to get trained and there is now a Budget that allows group training Sessions* to be organised. A train the Trainer session took place in London in June to allow Registries to provide standardized training for their centres.

Rosi Oneto mentioned the importance of concentrating their national training on Beginners initially. It would be a good effort towards bringing most of the Data Entry Users to a level of basic knowledge, before moving forward to advanced sessions.

Carmen stated that it is important to increase the training opportunities and to have a better contact with Centers in general. She raised the issue of a lack of training structure for the Eastern European Centres and efforts should be put towards training Trainers for that region.

Some good work has been done so far in regards to the translation of the revised Promise Manual as we now have a Spanish Version and the updated French Version which should be available in the beginning of the New Year. Some work is also being done for languages such as Dutch and Italian. That said, Carmen urges people to get involved in this project so that we can have more languages available.

A copy of Shelley's presentation is attached to the minutes for further reading.

**(for 10 or more Centres)*

3. Data Management Sessions at the Annual Meetings- Shelley Hewerdine

Med- B Sessions & Promise Training

Anja Van Biezen, from the Dutch registry, suggested a change in the content of Data Managing Educational Sessions. Instead of providing Med-B sessions, EBMT should have sessions which teach more about the diseases, the drugs, clinical information and the patient outcome. Keiren Towlson, from the British Registry, agrees and says that Data Managers need to learn more about diseases and treatments. Keiren also suggested that we could keep the Med-B sessions, but maybe to reduce it to one hour as an interactive session with a Panel to whom users can ask questions directly. Keiren recommends that we drop Med-B sessions for the 2008 Annual Meeting and change it to Data Managers Educational Sessions.

Carmen agrees and recommends that the Central Registry works on the content of those sessions to make it more interesting for the participants. She also thinks that the registrations to the Promise sessions should be managed by the Central Registry, to make sure only Promise Users and Data Managers have priority. Although it is short notice to make any changes for the Lyon Annual Meeting we will try to improve the sessions.

Keiren also thinks that the Promise sessions should be clearly aimed at Beginners or Advanced users to ensure the efficiency of the teaching provided at the Meetings. Plans for the EBMT 2008 Congress should be discussed at the 2007 Congress – RSC Meeting.

4. Semi Automated Quality Checks by the DRST – Presentation- Anja Müller

Anja Müller presented us the results of the Semi Automated Quality Checks performed by the DRST. Anja has been working on this program to improve the quality of the data provided by the German centres. Following the presentation, the German Registry was interested in setting up a collaborative group to pool resources on Data Quality Checking work and programs. This initiative was welcome.

You will find more information about her presentation as we are including them in the minutes.

5. Reports- Standardization

Carmen informed us about the standardization of Reports. She also suggests making general Registry reports public and more available for Data Managers. As they are publicly available, the reports should still be in accurate working order; otherwise they should be deleted or moved to private folders.

6. Promise Queries Module

Carmen presented the "MED-A missing Module" and the program will be posted on the website: <http://www.ebmt.org/4Registry/registry4.html#manual> – see **MED-A paper form merging (BETA version)**. She is suggesting keeping updated by reading the information on EBMT website and trying out the new program.

7. Excel Macros – Presentation- *Henk Jan Van der Wijk, Keiren Towlson*

Henk presented the results of his work on the Excel Macros, with the help of Keiren who has liaised with him regarding content suggestions and feedback. A manual on how to use them will be put together in the weeks to come and will be available on EBMT Website. It was felt that a lot more could have been said regarding this very much welcomed piece of work and the issue may be revisited during the Lyon RSC.

8. Centralization

Carmen informed us about the Board's decision to centralize Routine Registry work in EBMT's Paris Data Office. The process of centralization will officially start on the 1st January. The aim is to have it in place as soon as possible but because it is to be done with minimal disruption to existing personnel. It may take several months but no longer than a year. We will update information on the process at the EBMT Annual Meeting in Lyon.

9. EBMT WP request to Centres & their responses- *Rosi Oneto, Emmanuelle Polge*

Rosi and Emmanuelle presented their work on Standard Operating Procedures (SOP) for Registries and contacting centres for Retrospective Study data. You will find a summary of what has been agreed on the website and all registries must follow these SOP's when contacting centres:
<http://www.ebmt.org/4Registry/registry2.html#sop>

It is hoped that this will be the first of other documentation to help EBMT registry managers to work in a more organised and consensual manner.

10. Revision of MED-B Forms

Carmen informed the participants about the updating of the Med-B Forms, which is being coordinated in EBMT London Registry Office. The ALLO and AUTO Forms are almost finished. Other forms are being reviewed and will be updated shortly

11. Statistical Committee Request.

Myriam Labopin, on behalf of the Statistical Committee, has asked the Registry Data Managers to complete a questionnaire on items used/not used in studies by 20 December. The aim is to get an idea of which items are never used at all, and which Med-B items have to be requested all the time for studies.

*Actions arising from EBMT – Registries Sub Committee Meeting
26th October 2006
Paris*

| Action | Person Involved | Due Date if applicable |
|--|---|--|
| Members Database : 1-Give access to the Registries Data Managers 2- Updating information about Non-Members and Promise Users | 1-Sunil de Souza 2-Nathalie F-Robertson | Update on Progress at LYON-RSC |
| Promise Training for Centres: 1- Work on organizing a better Structure for providing Promise Training in Eastern Europe Centres, e.g. Training Trainers. | 1-Shelley Hewerdine | Update on Progress at LYON-RSC |
| Data Management Sessions at Annual Meetings: 1- Improve and update content for educational Sessions 2- Consider Plans for 2008 EBMT Meeting Concerning Data Management Sessions | 1-Shelley Hewerdine 2- All RSC | Update on Progress at LYON-RSC |
| Semi Automated Quality Checks by DRST 1-Setting up a Collaborative group to Pool Resources on Quality Checking Work and Programs | 1-Carmen Ruiz Anja Müller | Update on Progress at LYON-RSC |
| Reports- Standardization 1- Make sure that Publicly available Registry Reports/Exports are in accurate working Order. Delete any non accurate queries or move them to a private Folder. Provide the Central Office with a short summary of the output of each public report or export. (Ask Shelley for a Word version of Carmen's report descriptions if you prefer to use the same format) | 1- All RSC | Due now |
| Promise Queries Module 1- Information posted on website. Please keep updated | 1- All RSC | |
| Excel Macros 1- Create Manual on how to use the Macros | 1- Henk Jan Van der Wijk Keiren Towlson | We are also interested in viewing a more detailed Demo at LYON-RSC |
| Standard Operating Procedures (SOP) for Registries 1- Summary posted on EBMT Website | 1- Rosi Oneto Emmanuelle Polge | Available Now |
| Revision of MED-B Forms 1- Completion of ALLO and Auto 2- Review of the Other Forms | 1& 2 -Carmen Ruiz in conjunction with Definitions Committee & Working Parties | Update on Progress at LYON-RSC |
| Request from Statistical Committee 1-Questionnaire: Items used / Not used in Studies | 1. All RSC Data Managers | Please send to Myriam by December 20 th 2006 |