



REGISTRIES SUB COMMITTEE (RSC)

Minutes of the meeting held on 25th March 2007, Lyon. EBMT Annual Meeting

Participants: Carmen Ruiz (Chair); Sandra Allgaier; Helen Baldomero; Katerina Benesova; Virginie Chesnel; Zina Chir; Sunil de Souza; Corine Durand; Nathalie Fortin-Robertson; Shelley Hewerdine; Simona Iacobelli; 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; Hellmut Ottinger; Antonella Santucci; Barbara Bruno; Emanuele Angelucci; Ronald Brand; Hubert Schrezenmeier.

1. Return to Actions Points raised at the last RSC Meeting

Members Database –

We had a slow start and expected the transfer of data over to the MDB to be finalized in April. Carmen uploaded the centres now they are being updated and only about 500 Promise Users data need to be entered. The MDB should be complete and totally up to date as of mid-September 2007.

P2 Training/Outreach

Shelley was asked to attend the Outreach session during the congress.

Update: the EBMT has been invited to give Promise training at the National Haematology Congress in Ankara, Turkey in mid October. The training will be chaired by Carmen. In addition the registry office has been liaising with the Secretariat to produce a report on data management and in the future the aim is to secure more Outreach funding. They will report on methods of data submission and the completeness of data in Outreach and non Outreach countries.

Reports - Standardization

Carmen informed us that she is in the process of finalising documentation. (A catalogue of pre-programmed queries is now available on the ProMISe page of www.ebmt.org).

Med-B Forms:

CLLCLM, MDS, MPS, PCD, AL, Allo, DLI and Auto are to be implemented

SOP on Retrospective Studies:

*They are available now from the EBMT Website
<http://www.ebmt.org/4Registry/registry2.html#rsc>*

Excel Macros:

The presentation will be made available for everyone to read soon. Keiren and Henk Jan agreed to work on a user guide.

2. Data Managing Sessions in Firenze- EBMT 2008

Rosi Oneto and Barbara Bruno gave a few ideas and suggestions for this forecoming meeting :

Barbara suggested to have more information sessions to help Promise Users , perhaps have a Promise Information Room to ensure availability of Experienced Users to share their knowledge. Both Rosi and Barbara thought that the present Data Managing timetable doesn't allow enough time to support or answer Promise users's questions. Ideally people speaking different languages would be able to help Promise Users more efficiently, especially for people with a limited knowledge of English. Both also suggested that the information room could be useful if used as a Helpdesk with a few computers, and allow workshops on a smaller scale to take place.

Carmen questions the flexibility of the Data Managing Sessions and thinks the idea is interesting and is a reasonable request. Anja Van Biezen suggested to use this opportunity to help users create queries and store them in Promise for them to use. Carmen says that she will work at helping to organize arrangements for this idea.

Update : the Promise Open Learning Centre (OLC) has been approved and will be trialled in Florence. Shelley will contact registries nearer the time of the congress to organise a rota of volunteers to help in the OLC. A list of volunteers and their languages spoken will be advertised on the door of the room so that delegates can choose to visit at specific times if they prefer to seek help in their own language.

3. Change of Med-B Sessions

The programmes and content of Med-B sessions were discussed in previous meetings.

Anja Van Biezen has been working with Eduardo Olavarria on creating Templates on several diseases and the latest techniques used in treatment. She suggests to change the actual programme which goes through the MED-B question by question. The form can still be part of the presentation but shown only if there is a need or questions.

Instead, and Keiren Towlson agrees, a different approach could be used such as inviting a BMT Nurse to present the actual clinical process of a BMT. Keiren Suggests Michelle Kenyon, BMT Nurse from King's (UK) to chair. Anja also suggests that the Med-B sessions should be aimed at BMT Coordinators as well. Shelley Hewardine suggests the idea of sharing knowledge with the help of Experienced Data Managers, who would share their

work experience and methods; perhaps create a Data Collection Workshop. Marjon Smeets also thinks these sessions should have tips and hints for Junior Data Managers.

Carmen agrees and thinks it is now a priority to create a structure to organize new sessions and revise their content, but warns that it should not to move too far away from the Data aspect of these sessions.

It is agreed by all that the MED-B sessions shall be renamed and should now be called Educational Sessions.

Anja van Biezen and Keiren both volunteer to sit at a Med-B helpdesk. Keiren raises the fact that people who mainly use Promise to enter data might need help with the forms and also suggests that the Information Room be divided to allow a session and also provide a drop-in Helpdesk.

Carmen concludes and it is agreed that the format will change to Educational Sessions, divided in general sessions on Transplantation and a room with a Helpdesk which would provide a space for discussions and questions about Promise, data collections ; where National Registries could have a specified time slot for their members.

Update : The nurse's presentation on the transplant procedure from start to finish has been agreed. Shelley is liaising with the President of the Nurses Group who will confirm the speaker following their Board meeting in September.

The presentation from 1 or 2 experienced centre data managers has been included in the programme. Shelley is approaching contacts and suggestions are welcome.

The presentation from a study coordinator will also go ahead. Emmanuelle has volunteered to present on behalf of the ALWP.

There will be a discussion forum on Monday evening where data managers can ask further questions on MED-AB forms and data collection.

The sessions above, and the traditional MED-B sessions on specific graft types/diseases have been renamed « Educational Sessions ».

4. Data Quality Group Creation

It was agreed to create a Data Quality committee, to help automatize data quality checks and to establish a uniform procedure to check data quality. The German National Registry has already started work on this matter.

Once the group is created, its responsibility would be to create Standard Operating Procedures for Data Quality Checks. The following volunteered to be part of this group: Virginie Chesnel, Keiren Towlson, Sunil De Souza, Anja Müller, Beate Lindner & Nabila Elarouci.

5. Non-Existing / Non Reporting Centres

There have been questions about what to do with Non-Existing or Non-Reporting Centres.

Carmen asks about the loss of follow-ups

Keiren explains that in the British Registry, what she does is exclude any physically closed centre but keeps the data and keeps in contact with the physicians.

Ronald Brand explains how to lock a patient within the Promise Database so it can't be edited. It is also useful to know that there is a filter to ignore such centres when downloading/ viewing Data.

6. Follow-up procedures for Allo/Auto

Questions about Follow-up procedures:

Carmen states that in an Autograft, there should be a follow-up for a minimum of ten years. Helen Baldomero of the Swiss Registry asks for follow-ups for the first 5 years. After that period it's every 5 years for Allo and every 2 years for Auto. Keiren suggests to poll the PI's and submit results to the Board so that recommendations can be adopted by National Registries.

Update: Carmen investigated about Jacie rules regarding follow-ups and The Board does not recommend that we poll the centres. She will ask the Definitions Committee to give suggestions.