



## REGISTRIES SUB COMMITTEE (RSC)

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### Minutes of the meeting held on 19<sup>th</sup> March, EBMT 2006 Hamburg

*Participants:* Carmen Ruiz (Chair); Sandra Allgaier; Mutlu Arat; Andrea Bacigalupo; Helen Baldomero; Bo Björkstrand; Barbara Bruno; Katerina Benesova; Nivette Bragança; Ronald Brand; Virginie Chesnel; Zina Chir; Roisin Cinneide; Dennis Confer (NMDP); Sunil de Souza; Giorgio Dini; Nathalie Fortin-Robertson; Shelley Hewerdine; Mary Horowitz (CIBMTR); Simona Iacobelli; Jean-Pierre Jouet; Hana Krejcova; Rafael Linares; Beate Lindner; Anja Müller; Carlheinz Müller; Rosi Oneto; Hellmut Ottinger; Emmanuelle Polge; Bénédicte Samey; Antonella Santucci; Keiren Towlson; Anja van Biezen; Henk Jan van der Wijk; Marie Wilson

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#### **1. Report generation / "Train the Trainer" course in June 06**

Staff were invited to attend a 2-3 day course to be held at UCL, London in June. Carmen stated that all EBMT staff must attend due to importance of this training. (She recommended that representatives from each national registry should also attend). Following the preliminary training on Advanced Reports last summer, the course will provide further training so that registries can become familiar and confident in dealing with advanced queries.

In addition the course will involve a "Train the Trainer" session to assist staff who are already involved / interested in becoming involved in a pool of trainers that can provide ProMiSe training to centres. Carmen mentioned that she has led several group training sessions that have been organised through national meetings. In addition a training session will take place in Lund in April 2006 for Swedish data managers. The aim of the course is to standardise Promise training procedures across the EBMT and to increase the number of available trainers and assistants for future sessions. The range of languages spoken by the registry staff will also be helpful, particularly for sessions at a national level.

The registries present all agreed that they would try to send a representative from their registry and they are to contact Nathalie to confirm their availability.

#### **2. Donor Information in the Registry**

Helen reported that she has submitted a proposal to the EBMT Board, following the decision of the Swiss transplant registry to follow up all Swiss donors from January 2007. Other national registries were asked about plans for donor data within their organisation:

Germany: not registering donor data on a central basis, patient and donor registries are not integrated.

Austria: donor data remains in Austria. It will be stored in a separate, linkable system.

UK: 2 main registries of unrelated donors exist. They follow up their own donors using their own databases. There is a minimal collaboration between the transplant registry and donor registry, for example provision of engraftment data.

Italy: preparing donor registry in collaboration with a national agency.

For the CIBMTR, Mary Horowitz expressed an interest in developing a common data collection form. One important question was whether the transplant centres would be responsible for following related donors, and Mary suggested there should be a consensus from the community. There is also the question of whether the transplant registries will then be obliged to report serious adverse events relating to donors. The CIBMTR is developing a draft form for donors and a TED / MED-A form could be developed together with the EBMT. Carmen agreed that it would be a good idea to work together on this.

For the NMDP, Dennis Confer mentioned the importance of unifying principles and consideration on the following issues: early / late follow up; quality of life; related or unrelated and health insurance.

(A meeting of the donor registries will shortly take place in S. Africa where this issue will be discussed further).

### **3. Standardisation of Data Request Procedures**

Anja van Biezen reported that there were some difficulties in preparing data requests to send to centres. She would like to send them in a user-friendly format but there is a problem for the CLWP registry to generate requests in bulk for so many centres.

She asked how other registries approached this and what type of feedback they had from the centres:

Acute Leukaemia / Lymphoma registries: use a MED-B merge and email forms in Word showing the filled/missing data.

Some national registries prefer to send an Excel file with the missing data fields highlighted in block colour. Austria, UK, Swiss and Haemoglobinopathy registries all reported that they use this method and found it the most effective for getting the data back from centres. They found that the paper forms could be overwhelming for the recipients especially if many patients were being queried, and it was not so easy to see which data was missing.

Carmen asked if there was any manual work involved and recommended some improvements, for example creation of a macro to automatically highlight the missing data fields in Excel.

Henk Jan (who has created a more user-friendly Excel workbook in Promise exports) agreed to visit Keiren at the UK registry to discuss requirements and add some more enhancements to make this work easier for the registries.

Carmen mentioned that the report documentation is overdue. She is preparing a document with details on her pre-programmed advanced queries. Shelley has prepared three handouts for data retrieval training and these will be incorporated into the complete user manual.

There was also some complaint over the number of exports that had to be run in order to retrieve MED-B information. Carmen asked Ronald if he could add more slots in the advanced query builder. He cannot currently comply with this request due to problems with server overload.

### **4. Request for Missing Data: Module "Queries P"**

Carmen reported that she has created the above MS Access module to generate a report showing missing MED-A data. The program grabs full MED-A by transplant. With the help of Virginie, certain conditions have been applied so that centres are not asked for irrelevant missing items. Five registries have also assisted with the testing. There had been some technical problems with Access properties differing by country. When the testing is complete the module can be uploaded on the EBMT web site as soon as possible.

Anja van Biezen queried who should be responsible for carrying out data quality checks. Carmen confirmed that she regularly carries out checks at the Central Registry, and EBMT registries are also responsible for cleaning the data. Anja found that there was a lack of quality checks in the EBMT registries, especially when many centres are entering their own data in Promise.

Ronald pointed out the inefficiency in having several different registries carrying out their own checks. Carmen mentioned that she has already created some checking reports for users to load, and that the gradual centralisation of EBMT data management should help to solve these issues.

In connection with missing data in general, Beate mentioned that she had some difficulties in obtaining data from some centres in Austria, for example donor and follow up information. Carmen stated that centres simply had to fill in the forms properly, although collecting the data itself can be very time-consuming.

Mary Horowitz emphasised that full MED-B is needed to do good studies, but there is a problem with lack of personnel; time and funding. Carmen estimated that the MED-B reporting rate is 20%. It was suggested that an analysis on data reporting could be done. In the future the aim is to add a reporting profile to the members database. The Secretariat could collect information in membership application forms on the diseases that each centre is transplanting for.

### **5. Other Business**

Beate asked if there was a quicker way to enter bulk follow ups. She has an Excel file with survival status, relapse and cause of death. Carmen stressed that it was crucial to obtain more complete follow up information and that it should be entered directly through Promise due to data quality controls.

Ronald announced that he has written a draft manual on data reporting in connection with the new Beta test version of Promise 2. It gives a flavour of advanced report queries and survival analysis. Registries were recommended to attend Henk Jan's talk during the congress - on exporting data from Promise for survival analysis in SPSS and the new statistical portal.