



REGISTRIES SUB COMMITTEE (RSC)

Minutes of the meeting held on Sunday 29th March in Gothenburg

Participants:

Jude Aben (JA), Helen Baldomero (HB), Katerina Benesova (KB) ; Ronald Brand (RB), Virginie Chesnel (VC), Nabila Elarouci, (NE), Marlies Groenendijk (MG), Shelley Hewerdine (SH), Simona Iacobelli (SI), Chantal Kenzey (CK), Keiren Kirkland (KK), Camilla Kristiansson (CKr), Myriam Labopin (ML), Julia Lee (JL), Beate Lindner (BL), Helga Neidlinger (HN), Rosi Oneto (RO), Nicole Raus (NR), Carmen Ruiz, Chair (CR), Marijke Scholten (MS), Steven Tran (ST), Marie Trnkova (MT), Leonie Wilcox (LW), Marie Wilson (MW), Henk van der Wijk, (HVW),

1. Apologies

Emmanuelle Polge, Benedicte Samey, Dilek Dursen, Carmen Canals, Barbara Bruno, Florence Mesnil

2. Welcome new members

The Minutes of the last meeting were agreed as a true record.

CR introduced Steven Tran the new Information Analyst who works for the Registry in the office in London.

3. Annual Meeting (SH)

(a) Issues with 2009 Organisation

SH thanked everyone who helped prepare the meeting and to the volunteers assisting in the Promise training and Open learning Centre sessions.

SH said that it may be worthwhile to consider using a projector for the EBMT stand at next year's meeting in Vienna to display the registry slides. KK suggested that we could look at a digital frame; it will enable people to look at the slides they are interested in.

Action: SH to speak to Astrid

(b) Data Management Sessions at EBMT 2010

SH stated that we should start looking at next year's Data Manager's programme – Any suggestions are welcome before the end of June 2009 at the latest.

SH suggested that a session from the Data Quality group could be introduced.

Christina Peters, EBMT Chair of the Paediatric Diseases Working Party has agreed to give a lecture in Paediatrics during the Data Manager's session at the 2010 meeting in Vienna.

CR also stated the importance of keeping the input of the nurse's group as it is the only liaison we have with them at present. NE said that it would also be informative if we had the point of view of a statistician and ML put herself forward as a speaker for EBMT 2010 in Vienna.

Action: ML

Data Retrieval Sessions – it was agreed that we should not block new users from attending, but they should be clearly informed prior to registration exactly what they are signing up for. CR stated that we should keep good records of people who have undergone training and requested all trainers to provide names of attendees (whether group or one-to-one) to Jude or Shelley. It was discussed whether a certificate should be presented on completion of training and this was agreed to be done on request.

Action: ALL

4:0 Definitions Committee

(a) New representative for National Registries

CR informed the meeting that the Definitions Committee has been reconstituted with some old and new members. VC has taken over from RO. KK resigned from her seat as National Registries representative to the Committee and CR thanked her for her valuable input in the past. HB volunteered to take over this seat and the RSC voted a resounding yes.

CR reiterated that the role of the data manager is to make sure the wording of the manual is clear and that all items are properly described.

(b) Membership Rules

CR said that membership rules are that you can only sit on the Committee for a maximum of 4 years. National and EBMT Registry representatives are to be appointed by the RSC.

5:0 Data Quality Group reconstitutions

Membership – CR reminded everybody that during the meeting in Lyon it was decided to organize a steering group whose aim would be to ensure and sustain data quality. It was agreed that Virginie, Beate, Nabila, Helga, Keiren and Steven would be part of this group. CR explained to the meeting that the remit of this group is to prioritize the tasks which need developing e.g. missing data, wrong data, follow-up etc

Action: VC, BL, NE, HN, KK, and ST

Emmanuelle Polge was not present at the RSC but has since agreed to join the Data Quality Group.

(b) **QueriesP2 for 2008 Med-A** – VC to put together a document regarding how the Paris office deals with missing data requests: National registries can either manage this themselves or use the Paris office – Our aim is to automate queries as much as possible.

Action: VC

ST is finalizing the MED-A merge module used to generate filled forms with missing data highlighted. It is being updated to match the new MED-A form as the previous version was for pre-2008 MED-A. The EDO uses it to request missing data and follow-up. (Centres also use it to print completed MED-A's for JACIE accreditation without the missing data highlighted). ST stated that he is hoping to have the new module on the website before the end of April. All documentation has been updated. CR requested that SH tests the module and the documentation as a new user.

Action: SH

(c) Priorities (proposal to WP to identify essential fields)

CR stated that the RSC is to ask the Working Parties what the essential Med-B data is, because the Med-B form is far too long. We need to clarify essential Med-B data fields. The Board has suggested that centres filling complete Med-A or Med-B with a minimum of 3 years of continued reporting should be awarded a certificate for “Centre of Excellence” to encourage proper reporting.

CR stated that we need to know the definitions of “completion” for Med-A's and Med-B.

Myriam Labopin conducted a survey 4 years ago to see which data was being used when undertaking analysis – she stated that it resulted in that 80% of Med-B data fields could be taken out.

CR reiterated the importance of completing forms correctly, including annual follow-up. If this was not achieved the centres should not hold a certificate for “Centre of Excellence”. Myriam Labopin added that we should aim to summarise Med-A's, follow-up in a simple programme. CR stressed the need to write a proposal document to send to the Working Parties to request the essential fields. ML agreed to write the introduction to the proposal to explain the purpose from the statistics point of view; CR will add the purpose from the point of view of the definition of “complete reporting”. This will be sent to the heads of the Working Parties. CR will send a copy of the document to everyone for their comments.

Action: ML & CR

6:0 Registry Update (CR)

(a) Membership

CR discussed the collaboration with donor registries.

(i) The Swiss Registry has been storing donor information for more than a year.

(ii) Anthony Nolan Donor Registry request from centres detailed follow-up's on patients. They have agreed to use the EBMT Registry from now onwards rather than request centres to send the data to them independently. This was started 3 months ago. HLA will be provided. Anthony Nolan still do most of the work.

(iii) The German Registry have requested new fields for tissue repository information.. This would be for both related and unrelated donors.

HB stated that in Switzerland it is a legal requirement to provide donor follow-up unless a form has been signed stating they don't want to do it. Now they obtain the same information from the Registry.

(b) Implementation of new/edited forms (Cord Blood, AA)

CR has received the final draft for the Cord Blood Form. The standardized form was submitted to all European Cord banks for approval. Working on both Med-A and Med-B, it is obligatory to submit information to Cord Blood banks. CR suggested adding an insert to both forms.

CR added that the Aplastic Anaemia Form is currently being finalized.

(c) Manual Review

- The manual draft should be ready by the end of April. The only manual not yet ready is on MS.
- HB presented the activity survey form following collaboration between EBMT and 5 other societies on Cell therapy. A manual on cell therapy exists on the website: this will need to be reviewed.

Action: CR/Katerina LeBlanc to review Cell Therapy Manual.

7:0 Documentation (SH, HB, VC, CR, KK)

(a) SH stated that there is a link in the Promise Manuals page of the website to two documents on Excel Macros used in ProMISe downloads.: The BSBMT Guide to Study Spreadsheets and Henk Jan's User guide to Excel Macros. She has been asked to review the latter. In addition, the Med-AB manual is to be updated after the Definitions Committee. SH also stated that the Promise Guides on Date Entry and Data Retrieval have been updated.

Action: SH to review Henk Jan's User Guide to Excel macros, publish MED-AB manual update and put MED-A presentation on Website.

(b)SH requested that VC's Med-A presentation is published on the EBMT website.

(c) CR stated that the Train the Trainer for Data Retrieval Manual is now finished and in use.

Action: SH to circulate the Train the Trainer manual to all the RSC.

8:0 Educational Subcommittee and Promise Training (SH)

SH informed the meeting that Tamás Masszi from Budapest runs the EBMT Educational Subcommittee. Tamás is trying hard to raise the profile of training in EBMT and associated national societies. SH added if anyone is interested in advertising any Data Management training on the website, to let her know and she will liaise with Tamás.

Action: ALL

9:0 Issues on the use of the database (ALL)

(a) Outstanding Query Field

SH said we need to identify the person who enters queries in the field. We need to agree to a procedure:-

- Do we need more than one field?
- Separate fields for MED-A and MED-B study data?
- Pop-ups automatic or not?
- Is there any way to link to username of who asked the question?
- Hide items for all centres (please remove query)

Action: CR/SH/NE

(b) Patients Shared Across Centres

CR demonstrated which field to use in the database to give access to a patient who had a transplant in another centre.

(c) New Study Table

CR gave a presentation on behalf of Emmanuelle Polge and Bénédicte Samey on a new study table in Promise for working party studies. EP and BS are pleased with the first tests. RB suggested calling it an analysis table, but not to include retrospective study data. Two points were clarified: i) the MED-A question 'Is this patient included in a study?' relates to prospective studies only and bears no connection to this table on WP retrospective studies. ii) This new study table is **only** for EBMT office use. HN stated the importance of making the table visible to the National registries. Otherwise, data could be unwittingly erased when cleaning up double patient entries.

Action: CR to send further information

10:0 Developments – E-mail macro (NE)

NE gave a presentation on a new e-mail macro to manage data collection in stages. CR requested a copy of the presentation and suggested that NE writes instructions on how to use the macro and it was agreed to make it available to other users.

Action: NE

The meeting had to conclude here as we ran out of time. The rest of the Agenda is to be discussed via email.