

## **EBMT Definitions group (DG)**

The Definitions Group first met in 2004.

### Remit

The remit of the group is:

1. Reach consensus on definitions or other issues being debated which affect the data stored in the EBMT Registry
2. Be available for answering questions from data managers (filtered and routed through the Registry)
3. Ensure the definitions in the manual are up to date
4. Actively participate in editing the MED-AB forms when needed
5. Liaise with the respective WPs, the Board, the PI's and data managers of the centres to ensure everybody is informed of decisions regarding definitions, MED-AB forms or the Registry
6. Attend the face to face meeting that will take place on the Saturday before the Annual congress.

Although representing a particular working party, all members are expected to participate in all discussions in which they feel they have sufficient expertise or interest.

Currently the DG is coordinated by the Head of the Registry. It is her/his job to prepare and update the relevant documentation, organise and act as a facilitator during the meeting, and filter the data manager queries before they get to the committee.

Most of the activity takes place by e-mail and the main characteristic of the persons needed for the group is availability: they must have time to answer e-mails and, sometimes, read documents.

### Appointments

Each WP appoints a representative for 4 years. A WP representative is asked to resign on a new WP head being appointed. If a member wants to resign before that happens, s/he should inform the coordinator 2 or 3 months beforehand. The coordinator will approach the WP head to nominate a replacement.

The group includes two representatives of data management, one from the EBMT and one from a national registry. These two people are selected by the Data Registries Group and their length of stay is 4 years.

A representative of the CIBMTR is a permanent guest, is invited to the annual face to face meeting and is also part of the queries and answers that circulate by e-mail.

A representative of the EBMT Clinical Trials group is also a permanent guest, is invited to the annual face to face meeting and also receives the queries and answers that circulate by e-mail.

## **Person's specifications**

### WP representatives

Clinician expert in the field

Nominated by the current WP Chairman

Available on a general basis by e-mail

Interested in reaching consensus across WPs within the EBMT

Interested in reaching consensus with outside organisations collecting similar data

Familiar with the data collection forms

With a working knowledge of the Registry

### Data management representatives (National Registry and EBMT)

More than 2 years' experience in data management within the EBMT framework

Nominated by the Data Registries Group

Available on a general basis by e-mail

Very familiar with the data collection forms

Very familiar with the Registry

Currently active doing data entry and data reporting

## **Duties and Responsibilities**

### WP representatives

Answer e-mails regarding data managers' queries as routed by the Registry office

Help to edit the Med-AB Manual as needed by revising drafts written by the Registry office

Ensure there is a slot in the WP business meeting to inform the WP about the items being discussed at the DG.

- information on minor issues which do not require WP feedback but that may affect the way the WP deals with the data
- request a discussion within a WP regarding issues which require input (i.e. "reduced intensity")

Ensure the WP Chairman keeps the DG in mind when discussing issues at the Scientific Board

Suggest ways to advertise and raise the profile of the DG within the organisation

Bring back to the DG any requests regarding definitions raised by the WP

Ensure the WP does not implement data collection definitions independently from the rest of the EBMT

Provide advice to all WPs regarding the data to be collected through the standard Med-AB

Support and actively promote international standards for data collection in HSCT.

Support and actively promote international harmonization of standard data elements in the field.

### Data management representatives (National Registry and EBMT)

Provide the data management viewpoint to the DG stressing difficulties with language, time constraints, length of data collection forms, etc.

Help to edit the Med-AB Manual as needed by revising drafts written by the Registry office

Bring back to the DG any requests regarding definitions raised by EBMT, national registries or centres data management or statistical staff.

Suggest ways to advertise and raise the profile of the DG within the organisation

Support and actively promote international standards for data collection in HSCT.

Support and actively promote international harmonization of standard data elements in the field.

### Coordinator (Registry Office)

Prepare documentation for meetings

Ensure minutes are kept of all meeting and that they are distributed to the participants

Filter and forward to the DG queries coming from data managers

Ensure all queries are answered

Ensure answers are distributed as widely as possible, if necessary, through the circulation of a "Data Management News"

Update the manual and other EBMT documentation to agree with decisions made by the DG