The EBMT Registry

Current Data & News

Follow up

Missing follow up

During 2017, the Registry will launch the 5 year follow up project, targeting registrations whose last follow up was more than 5 years ago.

Number of centres by the % of patients with missing follow up

Clinical Trials and commercially sensitive information

Any trial data can be stored in the EBMT database and be hidden from the working parties so it cannot be used for studies, but can still be accessed by the centre itself.

The EBMT would use this data exclusively for reporting total numbers, which are never broken down neither by centre nor by country.

To hide the registration you need to answer the relevant question and enter the date when the data can be made available for research.

The new form and manual are now available at www.ebmt.org in the following sections:

Data Management > Registry structure > Data collection forms & manuals

To register the New Cell Therapy data in ProMiSe use codes 21 and 22.

New Cell Therapy Med-A Data Collection Form

A new expanded Cell Therapy Med-A form was introduced earlier this year by the EBMT Registry. The form was developed by the Cellular Therapy Registry Committee led by Chiara Bonini and implemented by the EBMT Registry team. It was also harmonised with the CIBMTR and Japanese Stem Cell Societies to make sure the same or comparable data is captured.

The Cell Therapy Registry (CTR) aims to collect data on stem cells, or progenitors or mature cells, such as T lymphocytes, unmanipulated, such as DLI, or sorted and/or cultured and/or genetically manipulated, such as CAR T cells, used for treatment in combination with hematopoietic stem cell transplantation or alone, and including advanced therapeutic medicinal products (ATMP), as well as data on the clinical characteristics and outcome of the patients.

The new form also contains detailed of laboratory manipulation for all types of cells before they are infused into the patient. They include: selection, modification, genetic engineering and others.

Registration Completeness

We aim to obtain 100% HSCT registrations from our members. However, a comparison with the Activity Survey which is conducted independently from the Registry shows that this is not the case. The trend towards less registrations being submitted to the EBMT Registry is worrying as it can introduce biases in the registry studies.

EBMT-CIBMTR AGNIS Project

This project is the collaboration between CIBMTR and EBMT to forward consented transplant data, submitted to the EBMT, to the CIBMTR FormNet system, via AGNIS, for EBMT members that wish to do so.

Since the beginning of 2016 there have been 23,746 accepted transplants submitted to FormNet, and from September 2016 , data from 47 centres have gone through automated submission.

New Med-A and Day 100 reporting

At the beginning of 2016, with the implementation of a new Med-A, Day 0 registration became the official policy of the EBMT. The old Med-A, which had one Registration form due for completion at Day 100, was replaced by 2 forms: a Registration form to be completed at Day 0, followed by a Day 100 form.

There were concerns that the Day 100 data would be less available as centres would register the transplant at Day 0, but would fail to remember to complete that data on Day 100.

New Med-A and Day 100 reporting

Type of transplant by year

Paediatric transplants by year

New registrations entered through ProMiSe during 2016:

Centres 27,831

National registries 5,011

EBMT 3,160

Total 36,002

Faster data

The interval between the transplant taking place and the HSCT data being entered into the Registry Database has been falling year on year and we are pleased to report that this trend continues.

2016- conclusions

2016 was an important year for the EBMT Registry. With your help we have:-

• Reached a milestone in the number of patients recorded in the Registry. We now have half a million patient records
• Chosen our supplier for the Registry Upgrade project: Elsevier.

We look forward to working with them in 2017 to begin the new project

• Started implementing the paper free Registry, increasing the use of internet data submission through ProMiSe and future systems.

• Adapted the MED-B data collection and entry to make it compatible with the new MED-A.

• Piloted the new Cell Therapy Med-A.

For further information visit: www.ebmt.org

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New Registry System

We are pleased to announce that we have recently appointed Elsevier to work on our new registry system. The development will be based on MACRO, a powerful, flexible and user friendly Electronic Data Capture system that can be customised further to meet EBMT Registry requirements.

We’ll keep you updated as the project progresses.