
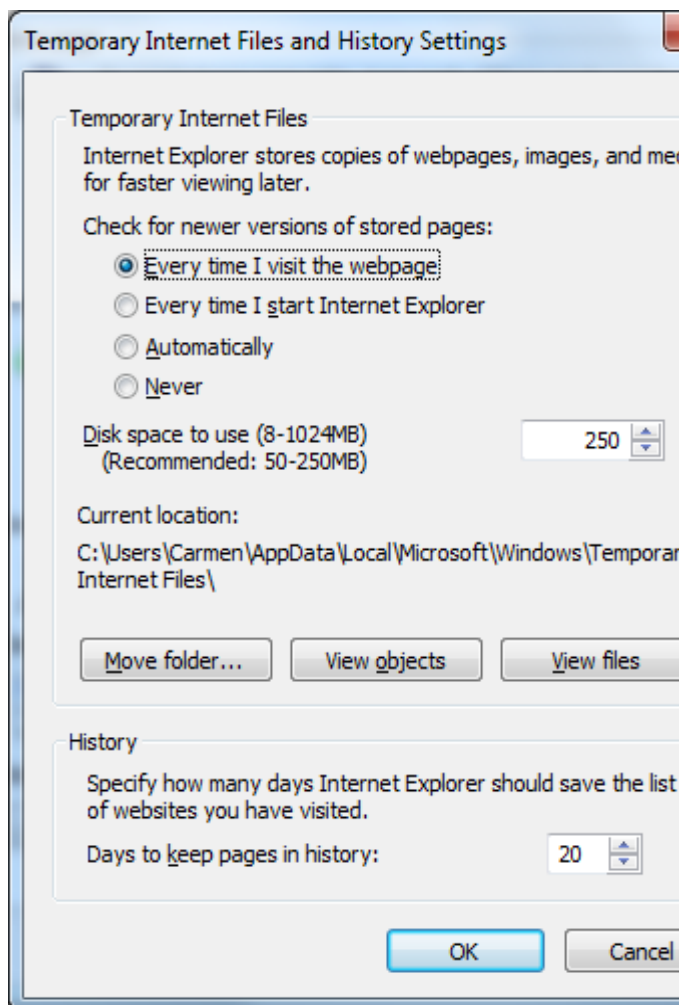


Important: ProMISe users with Internet Explorer 9

Please check you have the option “every time I visit the webpage” selected as below, otherwise you may experience problems with the display of results when retrieving data from ProMISe.

In Internet Explorer 9 click the Tools button , and then click **Internet options**.

Click the **General** tab, and then, under **Browsing history**, click **Settings**.



Centres submitting Med-A to the CIBMTR: New field in ProMISe for patient ID

At the beginning of the year, a new field named “CRID” was introduced to the EBMT Registry database to indicate the number being used for **CIBMTR patient (recipient) identification**.

Patient information	
Centre identification for transplant/therapy	
Name of unit or team	1 Haematology
Type of unit or team	
Contact person	
Area code where patient lived at time of HSCT (optional)	
Date of the 1st report	2007/02/22 2007/02/22
Date of the last report	2007/02/22 2007/02/22
CRID optional	Patient ID in CIBMTR forms.NET (to be used only if CRID known)
Patient in nat / international study / trial	1 No
UPN	1
Patient dossier number (Optional)	
Initial(s) first name	lu lu

Please enter the CRID exactly as it has been issued to you by the CIBMTR, otherwise leave the field blank

If the CRID is not yet known and EBMT has been asked by you to transfer your data to the CIBMTR, we will be supplied with a CRID by the CIBMTR and it will be entered on your behalf

You may notice that the CRID has already been added for any records your centre has previously submitted to the CIBMTR and for which the CIBMTR has been able to identify a CRID.

We hope that the data transfer will resume by the end of this year. We will keep you updated.

Data Management Sessions: EBMT 2012

Pamela Welton
 Data Management and Helpdesk Co-ordinator

We very much look forward to welcoming all participants in Geneva to the 11th Meeting of the Data Management Group, offering a varied programme of DATA MANAGEMENT EDUCATION SESSIONS and ProMISe TRAINING SESSIONS.

Click [here](#) to view the Data Management Programme.

Overleaf you will find information on a number of sessions to give you an idea of what will be on offer:-

JACIE Presentation

An orientation session aimed at everyone interested in the JACIE process

Peripheral Blood Stem Cell Harvesting for Transplantation (Curly Morris)

The first successful peripheral blood stem cell transplantations were carried out twenty five years ago in Heidelberg and a number of other centres. Factors which led to this highly effective new technique included knowledge of the circulation of primitive blood stem cells from marrow to blood (and back), development of large volume apheresis equipment, safe methods for cryopreservation of the harvested cells and a surrogate method for analysing their numbers. Within a short time the technique was improved by means of increasing stem cell numbers by use of chemotherapy, growth factors or both and its extension to allogeneic donors. Recent improvements have included techniques to successfully mobilize stem cells in hard to mobilize patients, although attempts to purify stem cell harvests or remove potential tumour contamination have been less successful. This presentation will look at the science underpinning these advances and on the data which is used to document them for use in future EBMT analyses.

Survivorship, follow up issues & patients' experiences (Michelle Kenyon)

This session will aim to define and explore survivorship in the BMT setting.

Using patient examples, this session will explore survivorship after BMT - issues experienced by BMT survivors as well as long term and late effects of treatment. The familiar MED-A follow-up data fields will provide a broad framework, to discuss clinical follow up and survivorship issues. Clinical issues will include long term issues and late effects such as infertility and conception, bone health, second cancers. Survivorship issues will include for example re-integration, work and finance, fatigue, relationships and quality of life following BMT.

The Importance of follow up forms (Simona Iacobelli)

Follow-up information is fundamental for any study in the field of stem cell transplantation, and more generally in medical research on diseases potentially with fatal exitus in the long term. This information is related not just to the duration of survival, but to any kind of event in the life and disease history of the patient, from those related to the disease status (achievement of complete remission, relapse, progression) to transplant-related consequences (graft-versus-host disease, infection) to administration of further transplants, and others. Statistical methods specific for "survival data" (more generally "time-to-event data") are used to identify relationships between patients' and transplant's characteristics and the occurrence of those events of interest. All investigations therefore need information collected before, during and after transplant, and in particular in "follow-up forms" - where we register the occurrence of events, with a date for each of them.

In the presentation, we will see through examples (either showing simple graphs of survival curves or illustrating schematic situations) the possible errors in the statistical evaluation, in particular seeing when the follow-up may be "too short", or "too poor" in terms of amount of censoring, and what could be the implications of having follow-up related to specific risk factors (including centre-related factors).

The aspects of my dual role in data management (Marie Trnkova)

This presentation describes Data Management work from a Centre's perspective and from the broader Registry view. The experiences from one centre help to understand problems and to find the right solutions. Data Managers in the centres often feel the working pressures, by contrast the Registry Data Manager may have to pressurise centres to provide the required data. Data Managers at every level have to exert their influence on all the important persons in the interest of co-operation and the common good.

Hints and tips for transplant registration with the EBMT (Carmen Ruiz)

This session will use the Med-A form as reference to indicate the essential data necessary to record HSCT data in the EBMT Registry database. We will be looking at a range of frequently asked questions:

- Which forms to use?
- Which procedures need not be reported?
- Who should report the data?
- Why are we collecting these data?

We will consider what information is required when reporting an HSCT and look at areas that frequently present difficulties in recording data, notably: Conditioning, Relapse, GvHD and HLA. We will also talk about Patient Consent. There will be some hints and tips to ensure your data is being accurately recorded and, of course, how to get help when you need it! This session can be seen as a complementary session to the Promise Data Entry session on Monday morning, but attendance of the course is not prerequisite. This will be an **interactive session** and you are welcome to bring along any relevant queries or problems—that you would like to discuss at the session.

Queries, questions and the first data quality quiz (Beate Lindner & Franziska Strehle for the Data Quality Group)

We will look at some queries (not only data quality queries) and show how they can be used for data checking, for identifying problem areas and for keeping an overview on our data. This session can be seen as a complementary session to the Promise data retrieval course, but attendance on the course is not prerequisite for this session. We will refer to some Promise queries, but focus on the questions behind queries and how queries can help us in our every day work. The quiz is open for all attendees and we are looking forward to seeing you there.

The use of monoclonal antibodies in the setting of HSCT (Silvia Montoto)

The advent of monoclonal antibodies (MoAb), especially of the antiCD20 rituximab, has revolutionised the management of patients with lymphoma. This has had a deep impact in the field of haematopoietic stem cell transplant. On the one hand, it has resulted in a change in the indications for transplant, given the better outcome of patients with lymphoma since the introduction of rituximab. On the other hand, the use of MoAb has also been incorporated in the strategy of HSCT and in some cases is an integral part of the treatment. MoAb can be used in many different ways to improve the outcome of patients having haematopoietic stem cell transplant for lymphoma: this, as well as the mechanisms of action of MoAb will be discussed at the Educational Session.

Paediatric Diseases (Isaac Yaniv)

Children are not just small adults. This is so true when we deal with stem cell transplantation. During the session we will discuss different disease categories of paediatric haematological malignancies. The session will allow data managers to better understand the specific paediatric SCT issues they are facing in their every day work. Children are different - not only because they suffer from different diseases, but also because their physiology, pharmacokinetics and responses to intensive therapy are so different from those observed in adults. All these factors, together with the very important psychological aspects involved, make the promotion of specialised paediatric transplant centres and teams a high priority of the paediatric diseases working party of the EBMT. Data managers are encouraged to send specific topics and questions they wish to be addressed during this session to the Speaker: isaac.yaniv@clalit.org.il.



Hematopoietic stem cell transplant for Solid Tumors (Didier Blaise)

Hematopoietic stem cell transplants (HSCT) for solid tumors are basically autologous transplants. These approaches have been developed in the mid 80's when it became obvious that Solid Tumours responded better to higher dose chemotherapies. However, increasing the dose of chemotherapy is associated with higher hematologic recovery leading to profound post-chemotherapy pancytopenia. After reaching a given chemotherapy intensity this leads to profound, long-lasting and in some cases definitive aplasia, incompatible with patient survival. In order to counter this limitation, HSC cryopreservation before and after high dose chemotherapy has been proposed and successfully performed. After 15 years of full development the results of this efficient approach have been challenged by the use of semi intensive sequential chemotherapy not necessitating hematopoietic stem cell support and by new targeted therapy. Although less widely used it remains a very attractive approach in some situations. Allogeneic HSCT has been proposed in a limited number of cases on a different perspective: it represents a form of immunotherapy as it is used in hematologic malignancies. The toxicity related to the procedure however impairs its wide development.

Acute Leukemia including ALL (Sebastian Giebel)

Acute leukemias are the most frequent indication for allogeneic hematopoietic stem cell transplantation (alloHSCT) with continued increases in the number of procedures over the last decade. Although characterized by common clinical presentation, acute leukemias are a very heterogenous group of entities, with different genetic background and phenotypic features. Precise description of the diagnosis implicates different treatment decisions, including indications for alloHSCT. Furthermore, clinical practice varies between national study groups and may influence the results of transplantation. The quality of reported data with regard to the diagnosis, therapy and assessment of the disease response is critical for interpretation of scientific analyses in a setting of acute leukemia.

Other educational sessions will

include: HLA; Outcome research in allogeneic transplant.

And finally..., on Monday evening there will be an opportunity to socialise with colleagues at the **Data Manager's reception** - look out for details at the congress!



ProMISe Training and practical workshop sessions:-

Data Entry: introductory session for new users to ProMISe illustrating how to enter a MED-A registration, subsequent transplants and patient follow-ups.

Data Retrieval: focusing on obtaining data listings, frequencies, report running. The session is open to all users but not recommended for people who are absolute beginners.

HLA Data Entry: focusing on how to enter HLA typing reports for those users who want to do it themselves. This session will build on the morning's [HLA Educational session](#) and is aimed primarily at experienced ProMISe users.

Advanced Data Entry (including MED-B) & Q&A training session: Med-B data entry with examples of complex data including: missing data, follow ups, subsequent diagnoses and transplants. Followed by a practical Q&A session.



Please register in advance for ProMISe sessions - spaces are still available for some sessions and booking details are on our [Education web page](#)