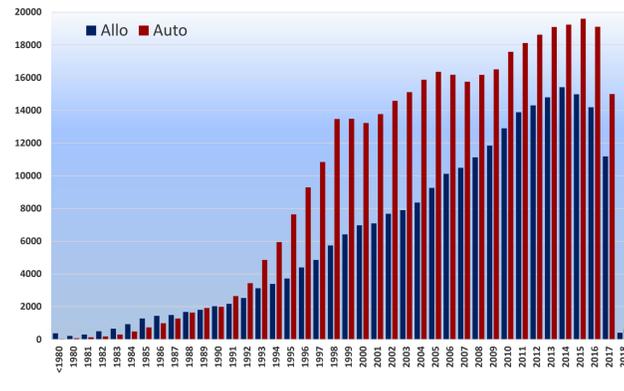


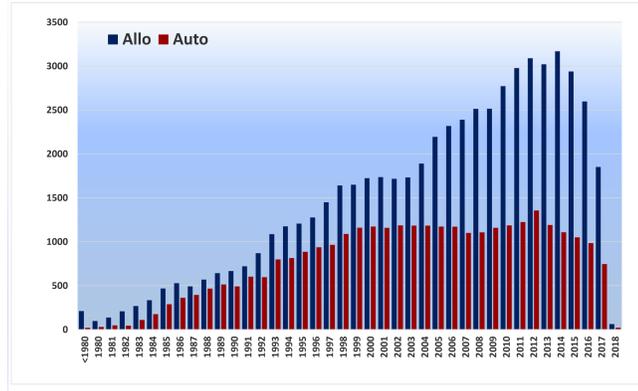
EBMT Registry Overview

Disease	Patients	Transplants
Acute leukaemias: AML	85,919	94,388
Acute leukaemias: ALL	47,820	51,615
Acute leukaemias: other/unknown	3,056	3,400
Chronic leukaemias: CML	21,793	23,478
Chronic leukaemias: CLL	6,836	7,515
Chronic leukaemias: other/unknown	1,003	1,106
Lymphomas: NHL	103,681	115,262
Lymphomas: Hodgkins	34,930	40,518
Lymphomas: other/unknown	1,702	1,817
Multiple myeloma/Plasma cell disorders	123,347	166,322
Solid tumours	42,738	58,073
Myelodysplastic/Myeloproliferative	32,114	35,954
Bone marrow failure	12,952	14,308
Primary immune deficiency	5,757	6,475
Inborn errors: other / unspecified	2,452	2,762
Histiocytic	1,439	1,578
Autoimmune diseases	2,570	2,627
Haemoglobinopathies	6,377	6,707
Other/unknown	258	299
Total:	536,744	634,204

Type of transplant by year



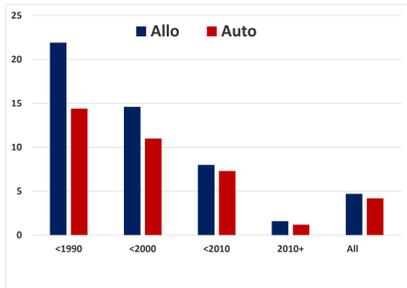
Paediatric transplants by year



Follow up

Long term follow up is essential for research. It helps us understand what can benefit or harm a patient, not only around the time of treatment but years after the event. It is essential that we keep up the effort.

Median follow up in years by period when HSCT was performed



Internet data entry

Who is entering our data?

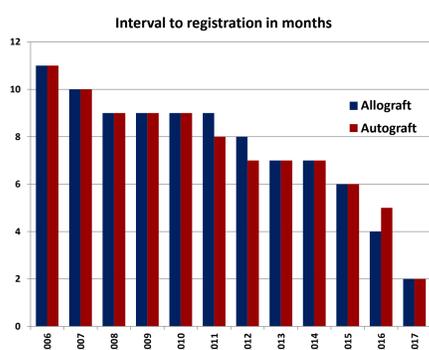
The number of centres doing their own data entry showed a detectable increase, with **580** users from **449** centres accessing ProMiSe to enter at least **5** registrations during 2017.

New registrations entered through ProMiSe during 2017

	Patients	Transplants
Centres	30,557	33,639
National registries	3,590	4,135
EBMT	1,503	1,930
Total	35,650	39,704

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



MACRO

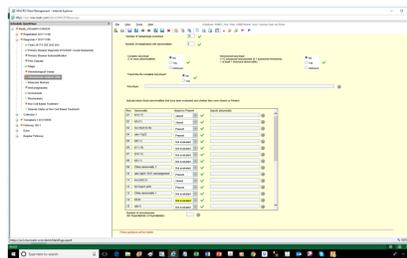
New Registry System

Background

Elsevier was appointed just prior to the last annual meeting to work on the new registry system. The development is based on their Electronic Data Capture system: MACRO. In Summer 2017, Nigel Brook joined the EBMT as Project Manager

Solutions

The enthusiastic team at Elsevier provided us with solutions to registry issues that exceeded our expectations. Benefits of MACRO include simple screens in Data Entry, easier ways to report more complex cases with multiple diagnoses and separate tests and assessments for each disease; faster entry of cytogenetics, drugs and other test results into tables instead of creating individual records:



Testing

Staff at the EBMT Registry have been involved in the initial testing of the Registry Design. We have recently expanded our pool of testers and a number of National Registry staff and centre data managers have volunteered to devote some of their time. We are very grateful for their support.

MACRO at EBMT 2018

Demo presentation from MACRO (Oli Cram & Ronald Schravendeel, Elsevier)

Monday 09:00 – 9:40 / Tuesday 14:00 – 14:40
Auditorium III

Practical session on MACRO. A taster of the new system (Carmen Ruiz de Elvira, EBMT Registry)

Monday 09:45 – 12:30 / Tuesday 14:45 – 17:35
Auditorium IV (Computer room). For participants who have pre-booked

Timeline

As the development programme takes shape we have been able to set some targets. Software development is only part of the project. The provision of adequate documentation and training are just as important. Our aim is to create a sufficient buffer so that end dates need not be changed even if some activities end up being delayed. Key project workstreams are shown below. As can be seen, our current working date for go-live is November 2018.

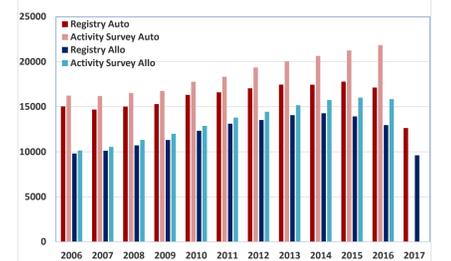


Registration Completeness

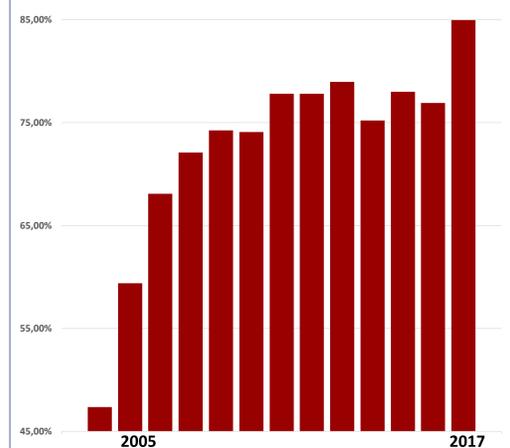
We aim to obtain 100% HSCT registrations from our members. However, a comparison with the Activity Survey which is conducted independently from the Registry shows that this is not the case. The trend towards less registrations being submitted to the EBMT Registry is worrying as it can introduce biases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

Make sure you report all transplants

Number of transplants reported to the Activity Survey and EBMT Registry by centres known in both systems



% Data entry done by centres



New General Data Protection Regulation (GDPR 2016/679) Is your centre ready?

- To ensure the maximum accordance with the law of all EU/EEA nations, all individuals residing in EU member countries must give informed consent for their personal data to be entered into EBMT type registries.
- If you request that the EBMT forward data to other organisations, it is the centre's responsibility to ensure that the patients have given consent for their personal data to be also sent to these organisations.
- Patients should be made aware of their rights when signing the consent:
 - Access to their data.
 - Rectification of any inaccurate or incomplete personal data.
 - Withdraw consent at any point and their personal data will no longer be made available for studies
 - Request that their personal data be completely erased from the EBMT Registry database and from databases to which the data has been exported.

2017- Conclusions

This year the Registry has benefited from:

- Faster data:** the interval between transplant and registration in the database continues to narrow
- Direct data entry:** the Registry strives to keep paper free and we have seen a marked increase in the number of centres entering their own data

However, areas for improvement are:

- Registration completeness:** We do not receive reports on all transplants per centre when making comparisons with the Activity Survey.
- Follow up:** it is essential to keep up the effort for our research

Thank you to all of our contributors for their collaboration and support