The EBMT Registry

Current Data & News

EBMT European Society for Blood and Marrow Transplantation

EBMT Registry Overview

Disease	Patients	Transplants
Acute leukaemias: AML	79,683	87,517
Acute leukaemias: ALL	45,504	49,071
Acute leukaemias: other/unknown	2,859	3,177
Chronic leukaemias: CML	21,488	23,138
Chronic leukaemias: CLL	6,655	7,324
Chronic leukaemias: other/unknown	903	999
Lymphomas: NHL	97,347	108,174
Lymphomas: Hodgkins	33,003	38,226
Lymphomas: other/unknown	1,673	1,786
Multiple myeloma/Plasma cell disorders	113,345	153,070
Solid tumours	41,504	56,221
Myelodysplastic/Myeloproliferative	29,626	33,194
Bone marrow failure	12,238	13,500
Primary immune deficiency	5,338	6,031
Inborn errors: other / unspecified	2,298	2,593
Histiocytic	1,354	1,485
Autoimmune diseases	2,261	2,316
Haemoglobinopathies	5,990	6,303
Other/unknown	240	276
Total:	**503,309**	**594,401**

Type of transplant by year
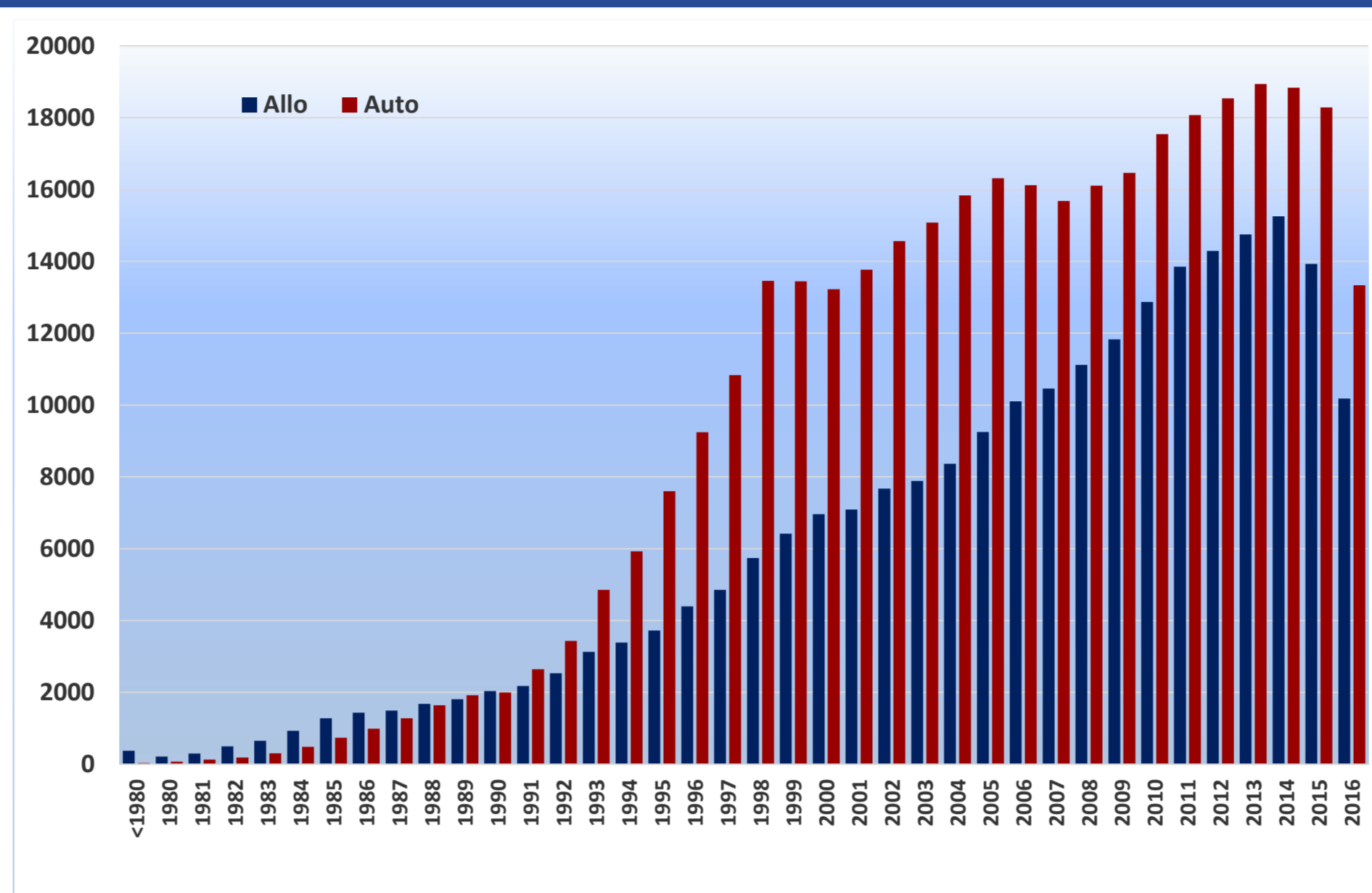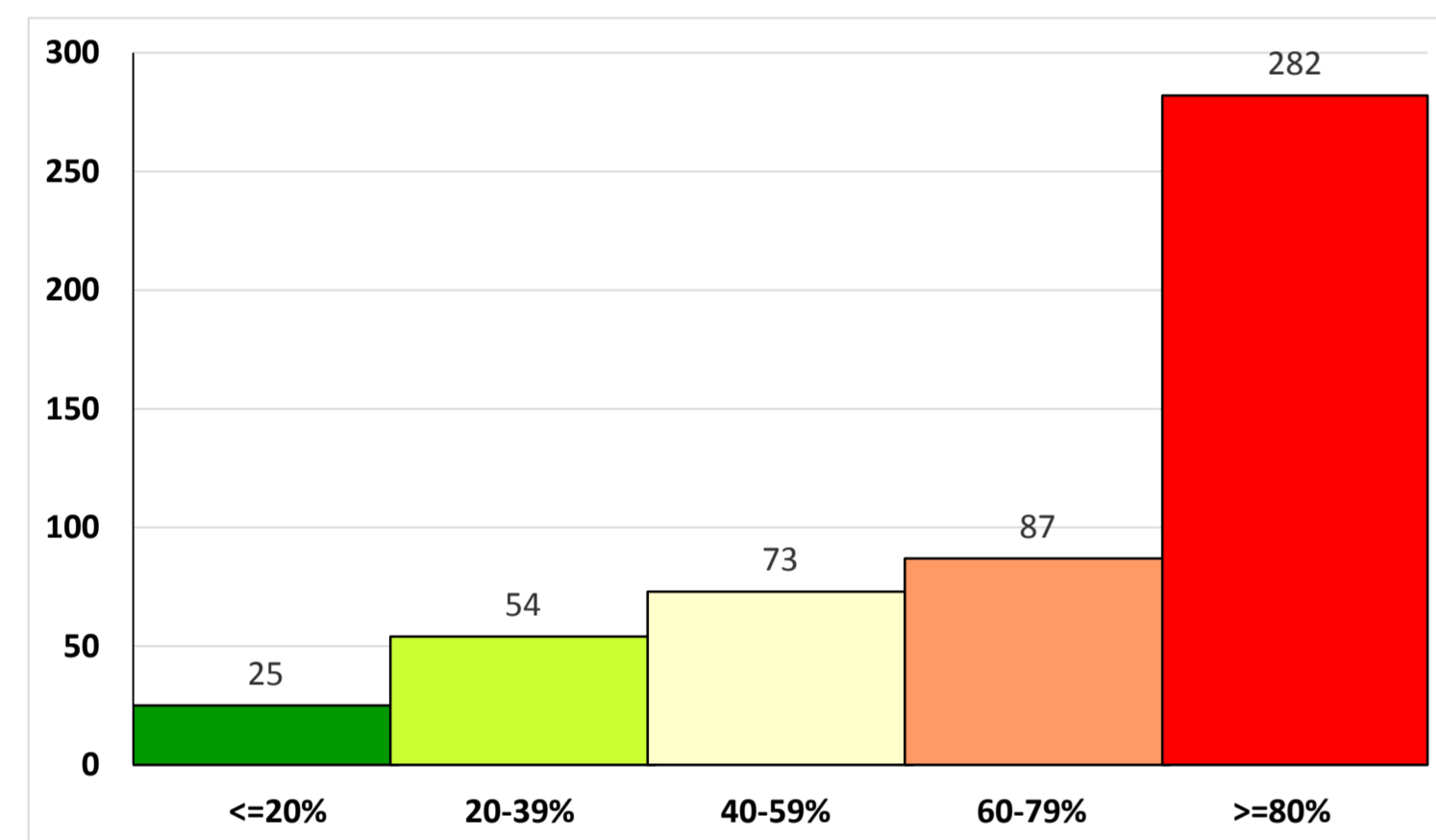

Paediatric transplants by year
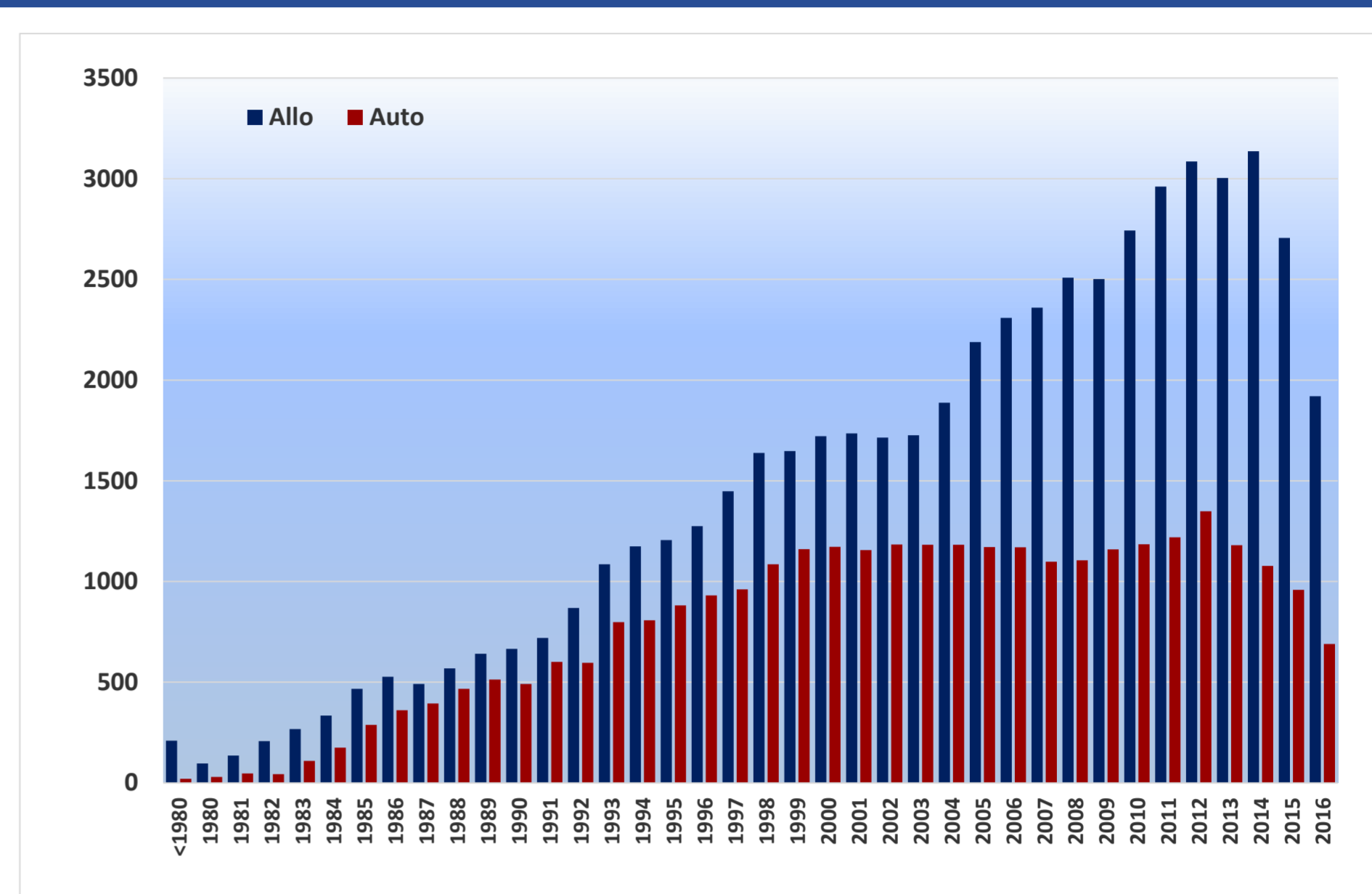
Follow up

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

Internet data entry

Who is entering our data?

Access through ProMISe showed a small increase during 2016.

505 users from **399** centres have accessed the database for entering at least **5** registrations during 2016 :

New registrations entered through ProMISe during 2016		
	Patients	**Transplants**
Centres	27,831	30,613
National registries	5,011	5,702
EBMT	3,160	3,753
Total	**36,002**	**40,068**

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 collects details of **laboratory manipulation** for all types of cells before they are infused into the patient. They include: selection, modification, genetic engineering and others.
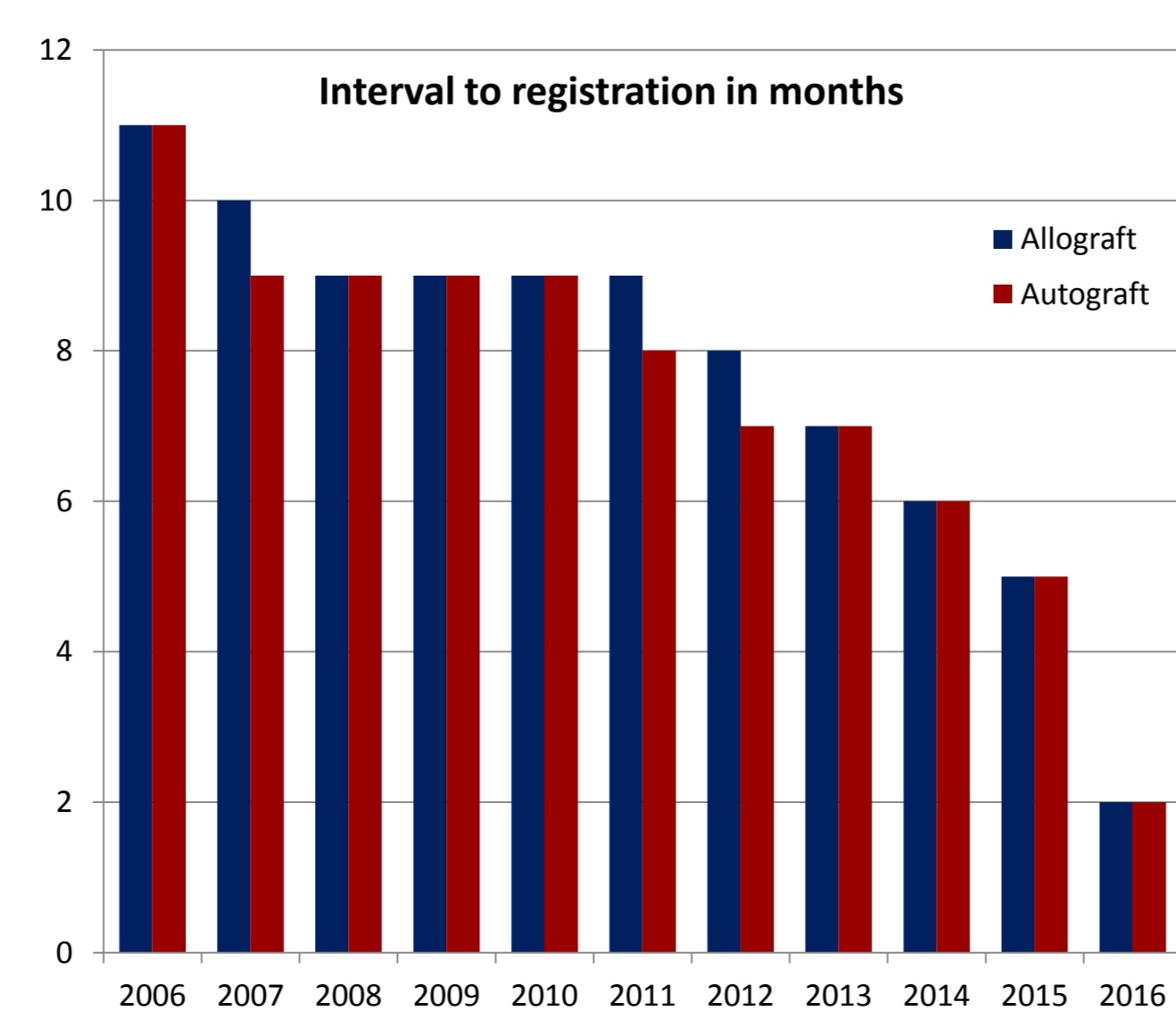

Clinical Trials and commercially sensitive information

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.

☐ Tick here if you want this registration hidden until .... - .... - ....
(indicate by which date the registration can be made available for research)   yyyy   mm   dd

The new form and manual are now available at **www.ebmt.org** in the following section: *Data Management > Registry structure > Data collection forms & manuals*

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

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.
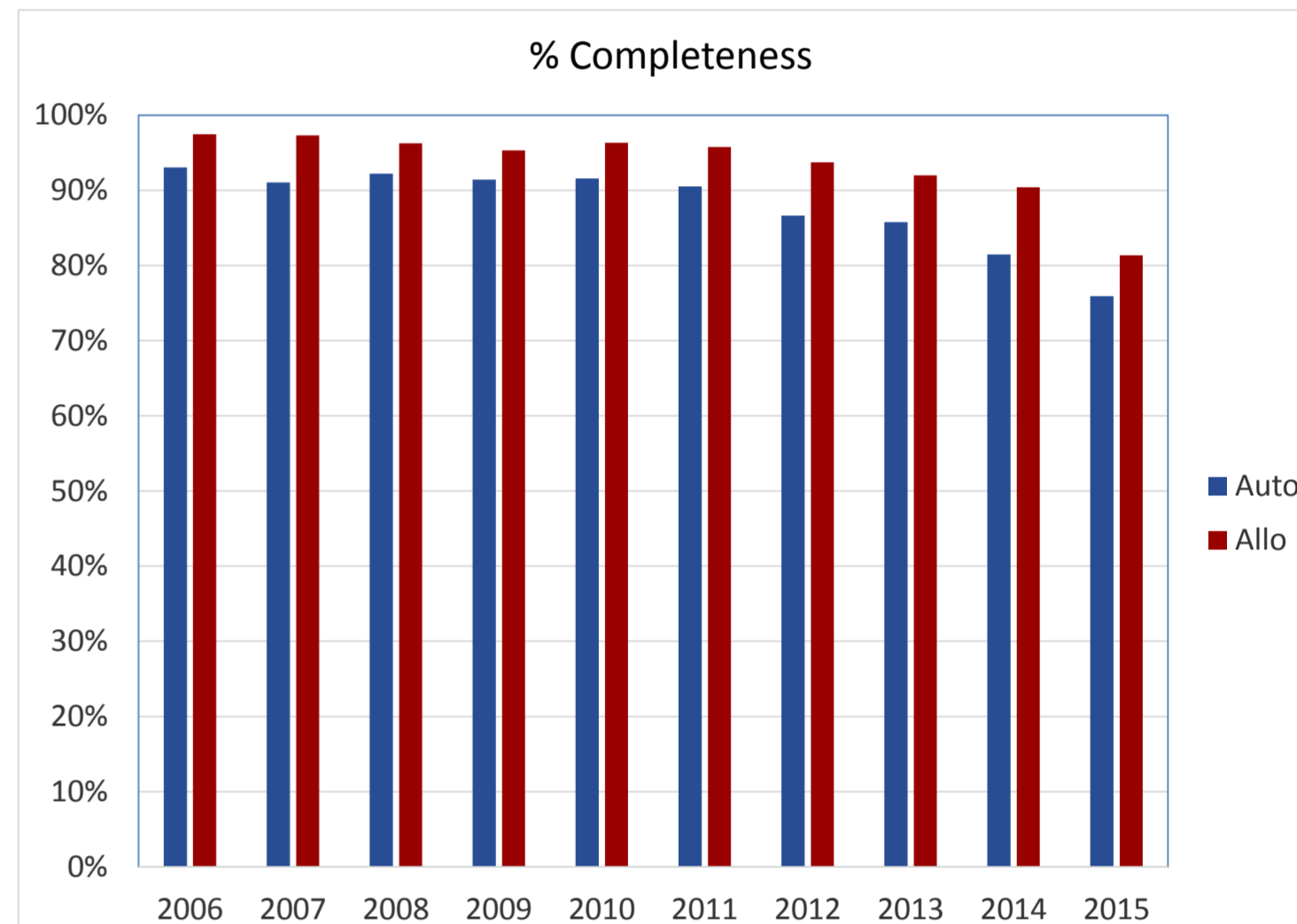
EBMT-CIBMTR AGNIS Project

This project is the collaboration between CIBMTR and EBMT to forward consented transplant data, submitted to the EBMT, to the CIBMTR FormsNet 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 FormsNet, and from September 2016 , data from 47 centres have gone through automated submission.

Forms submitted and accepted

Form equivalence and number	Since 2011	Jan 2016 to Jan 2017	Sept 2016 - Jan 2017 (automated)
Registration			
2804	38,098	18,952	9,001
2814	13,540	11,370	8,801
Med-A Day 0			
2400	9,796	4,370	1,695
Med-A Day 100			
2450 100 d	6,238	1,332	887
Med-A Follow up			
2450 6m	444	280	94
2450 1yr	572	343	28
2450 2yr	376	231	15
2450 3yr	243	125	5
2450 4yr	164	94	8
2450 5yr	137	70	8
2450 6yr	62	25	4
2450 7yr	5	5	-
2450 8yr	2	2	1
Product detail (USA Cord blood only)			
2006	125	-	-
Total	**69,802**	**37,199**	**20,547**

MACRO 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.

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.

Preliminary analysis of transplants registered during 2016 indicates that the completion rate of Day 100 updates stood at **76%** at the beginning of 2017, which is a reasonable percentage.

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. Cell Therapy data entry training is here at EBMT 2017