



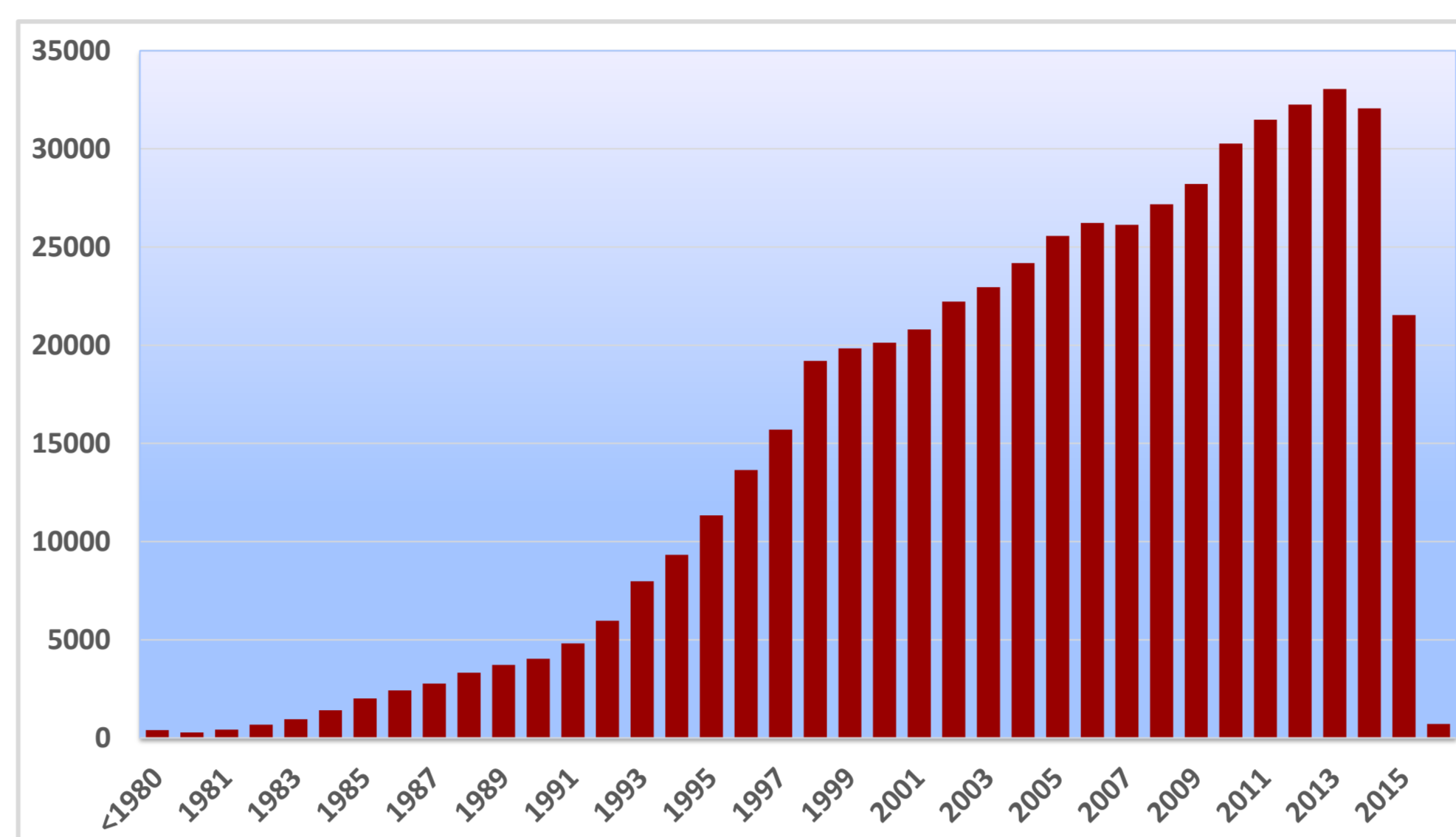
The EBMT Registry

The data

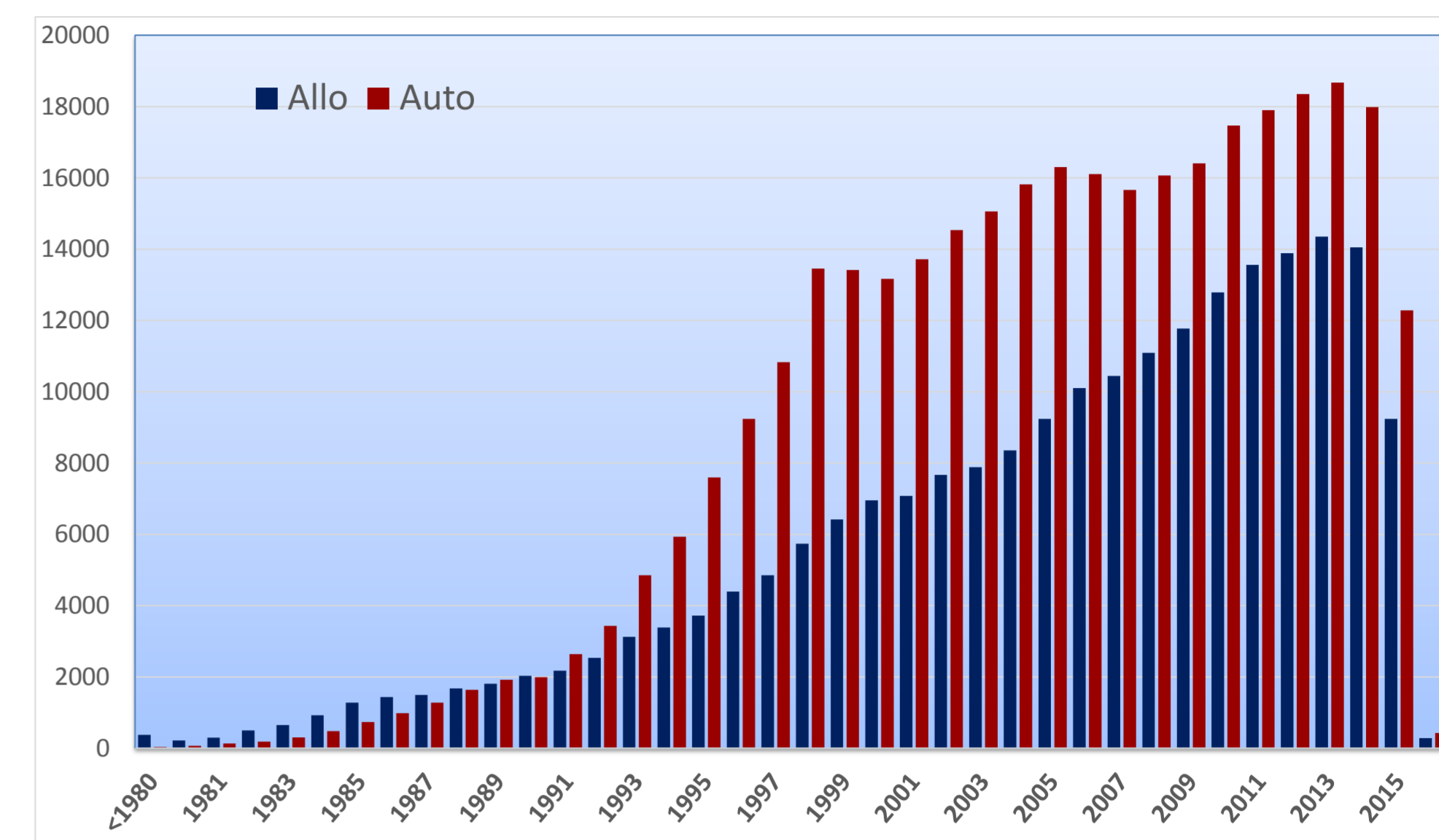
EBMT Registry

Disease	Patients	Transplants
Acute leukaemias: AML	69,400	76,053
Acute leukaemias: ALL	42,456	45,762
Acute leukaemias: other/unknown	2,460	2,742
Chronic leukaemias: CML	21,090	22,714
Chronic leukaemias: CLL	6,465	7,128
Chronic leukaemias: other/unknown	823	910
Lymphomas: NHL	91,560	101,781
Lymphomas: Hodgkins	31,357	36,216
Lymphomas: other/unknown	1,653	1,762
Multiple myeloma/Plasma cell disorders	103,746	140,342
Solid tumours	40,072	54,181
Myelodysplastic/Myeloproliferative	31,888	35,871
Bone marrow failure	11,370	12,523
Primary immune deficiency	4,779	5,407
Inborn errors: other / unspecified	2,133	2,402
Histiocytic	1,218	1,336
Autoimmune diseases	2,050	2,102
Haemoglobinopathies	5,540	5,829
Other/unknown	199	230
Total:	470,259	555,292

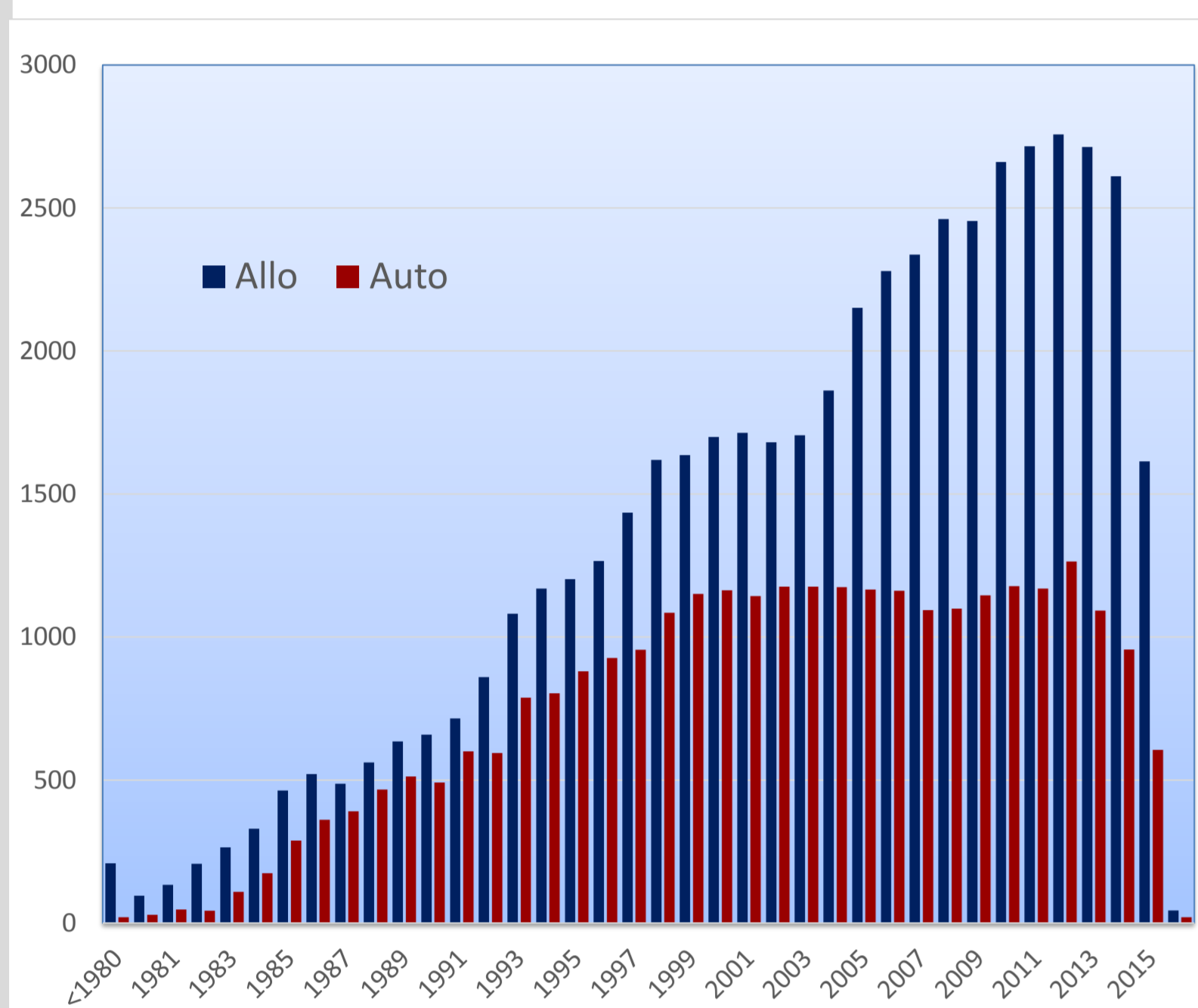
Number of transplants by year



Type of transplant by year

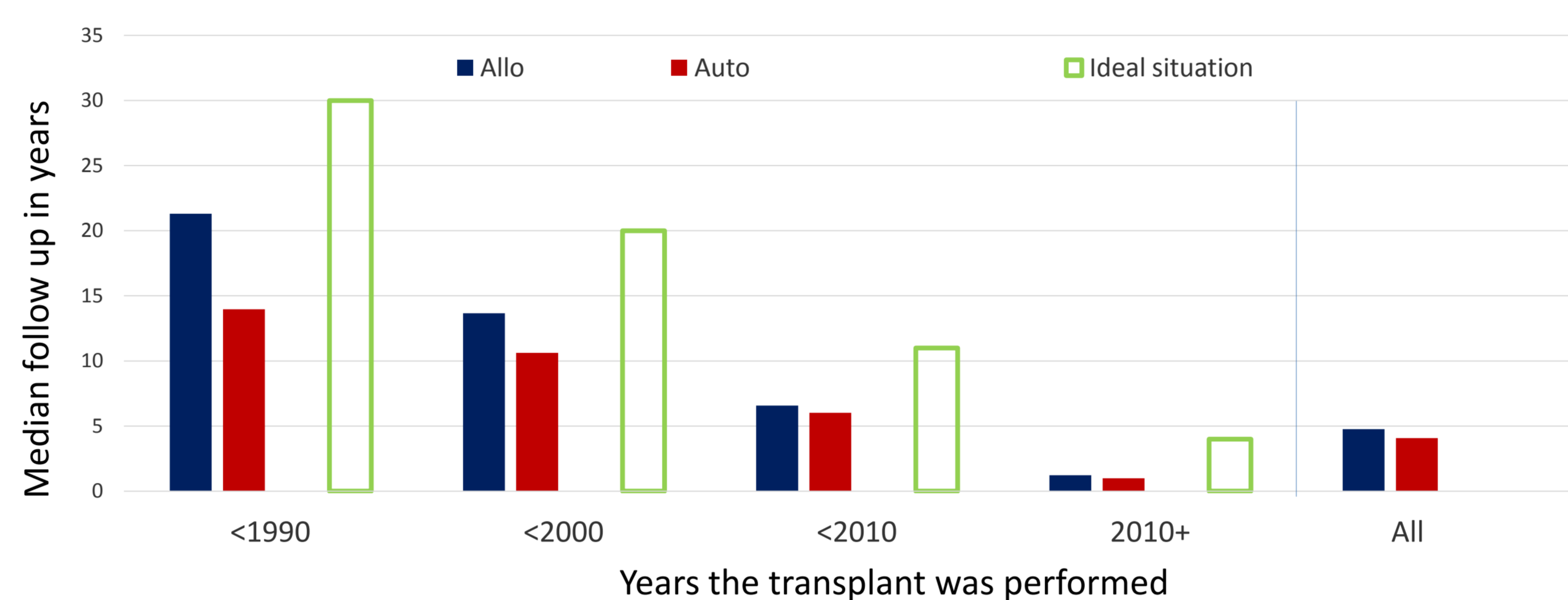


Paediatric transplants by year



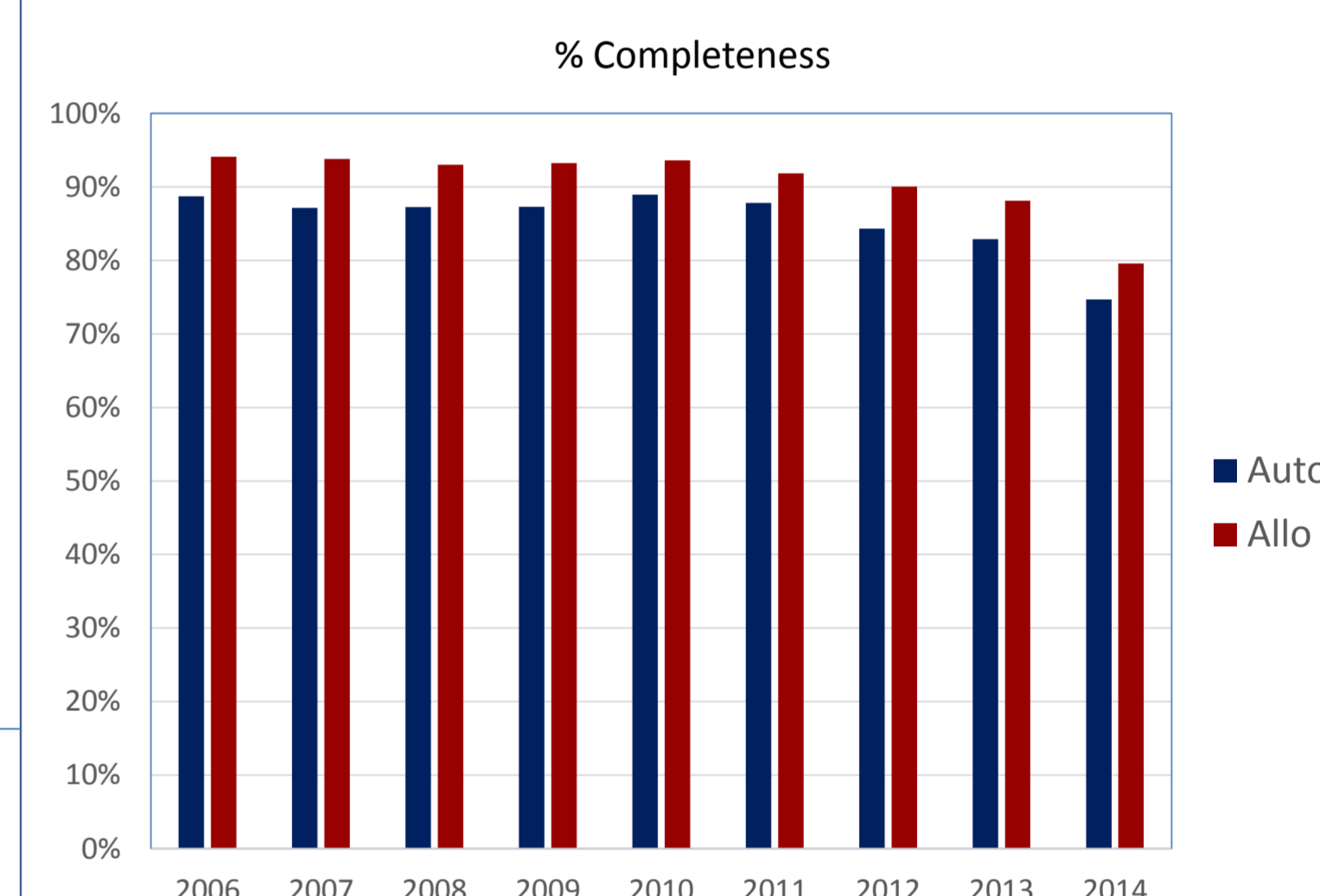
Follow up

Median follow up is far from optimal. The graph below shows the median follow up per decade and the ideal follow up had all patients been followed until today or death.



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.



Internet data entry

Who is entering our data?

Access through ProMISe continued during 2015 – but has slightly decreased. **495** users from **375** centres have accessed the database for entering at least **5** registrations during 2015 :

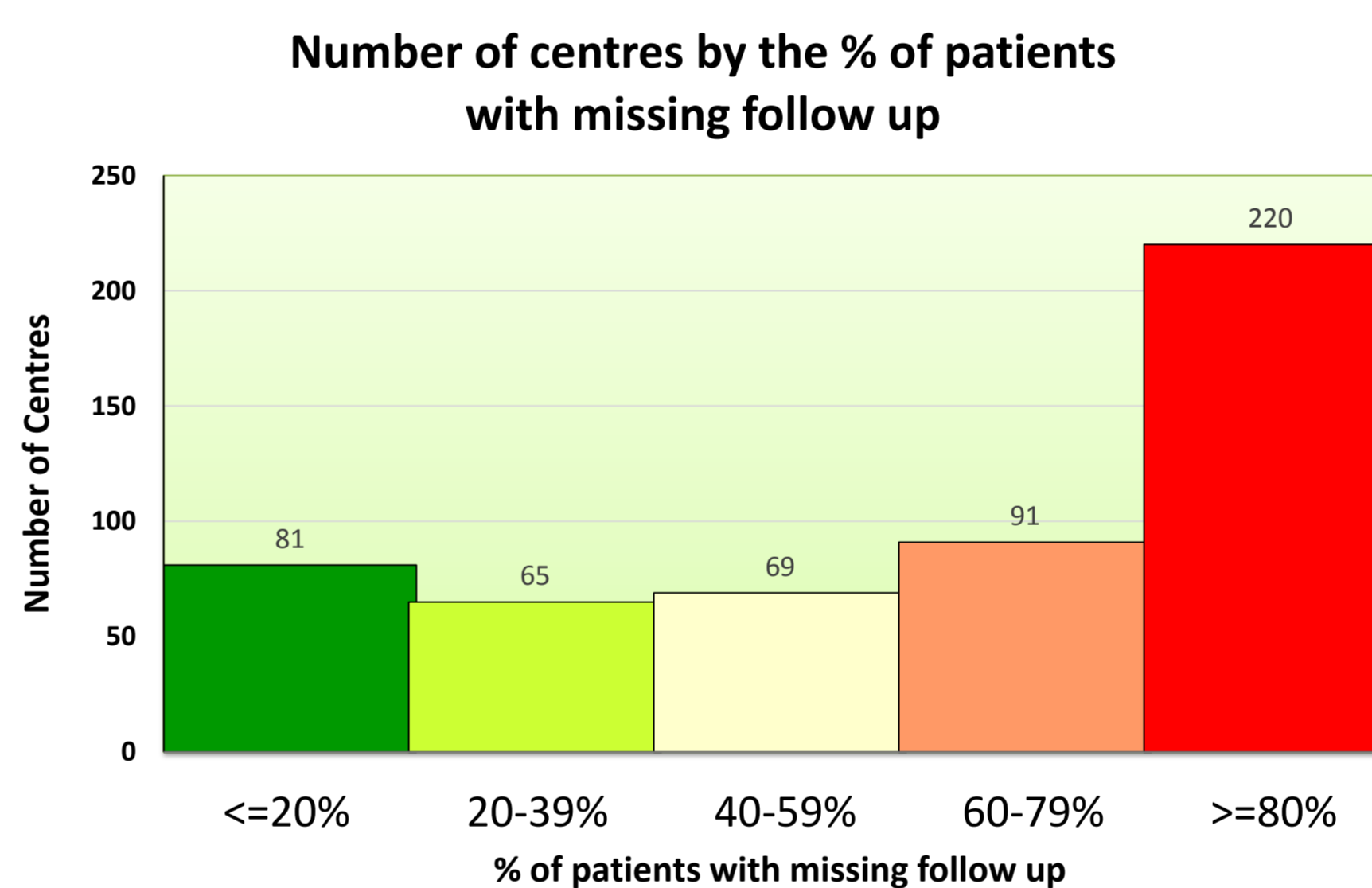
New registrations entered through ProMISe during 2015

	Patients	Transplants
Centres	25,542	27,529
National registries	4,259	4,854
EBMT	2,685	2,865
Total	32,486	35,248

How complete is your data? Where is your centre?

The histogram below subdivides centres according to follow-up completeness*

Make a guess!
Tell a Registry representative in what group you think your centre is.
We will tell you if you are right



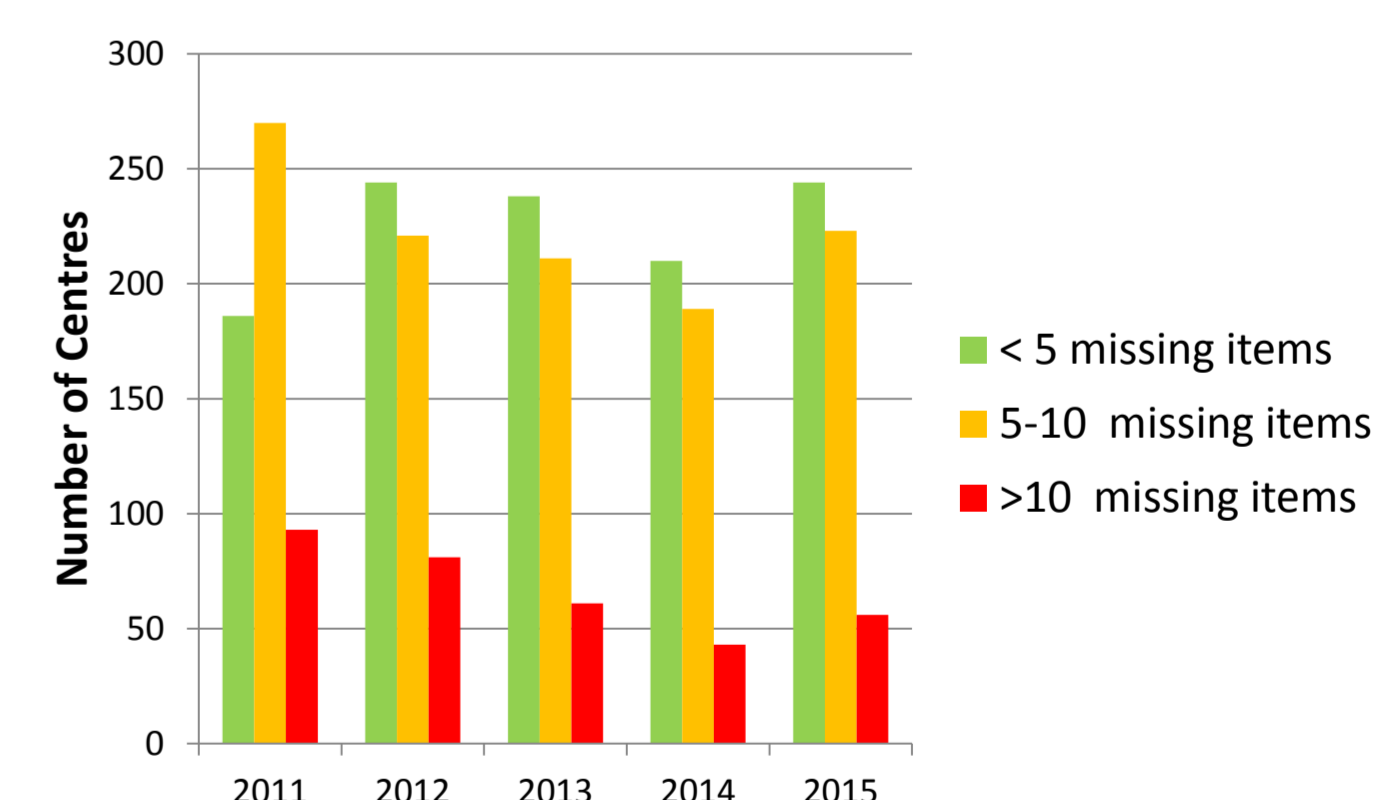
**Completeness is defined according to the following parameters:

- HSCT date less than 10 years ago → follow up every year
- HSCT date 10-20 years ago → follow up every 2 years
- HSCT more than 20 years ago → follow up every 5 years

Average number of missing items per Med-A

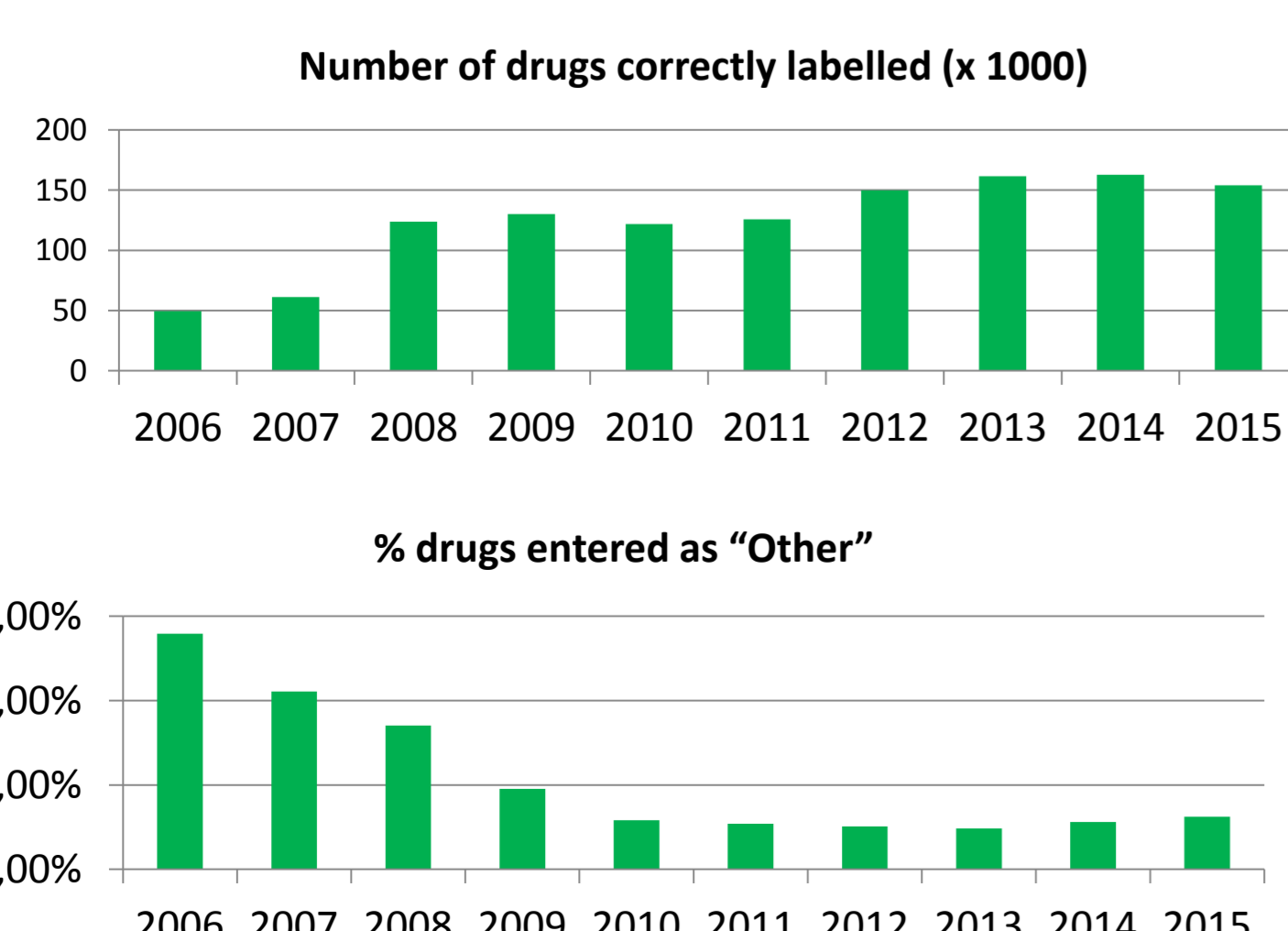
The Med-A represents the Minimum Essential Data needed to register an HSCT and all data items should be completed.

An analysis of the number of HSCT registered during the last 5 years and the levels of missing data in Med-A indicate that we are still away from achieving completeness. For reference, the average number of items filled in a Med-A is between 150 and 200.



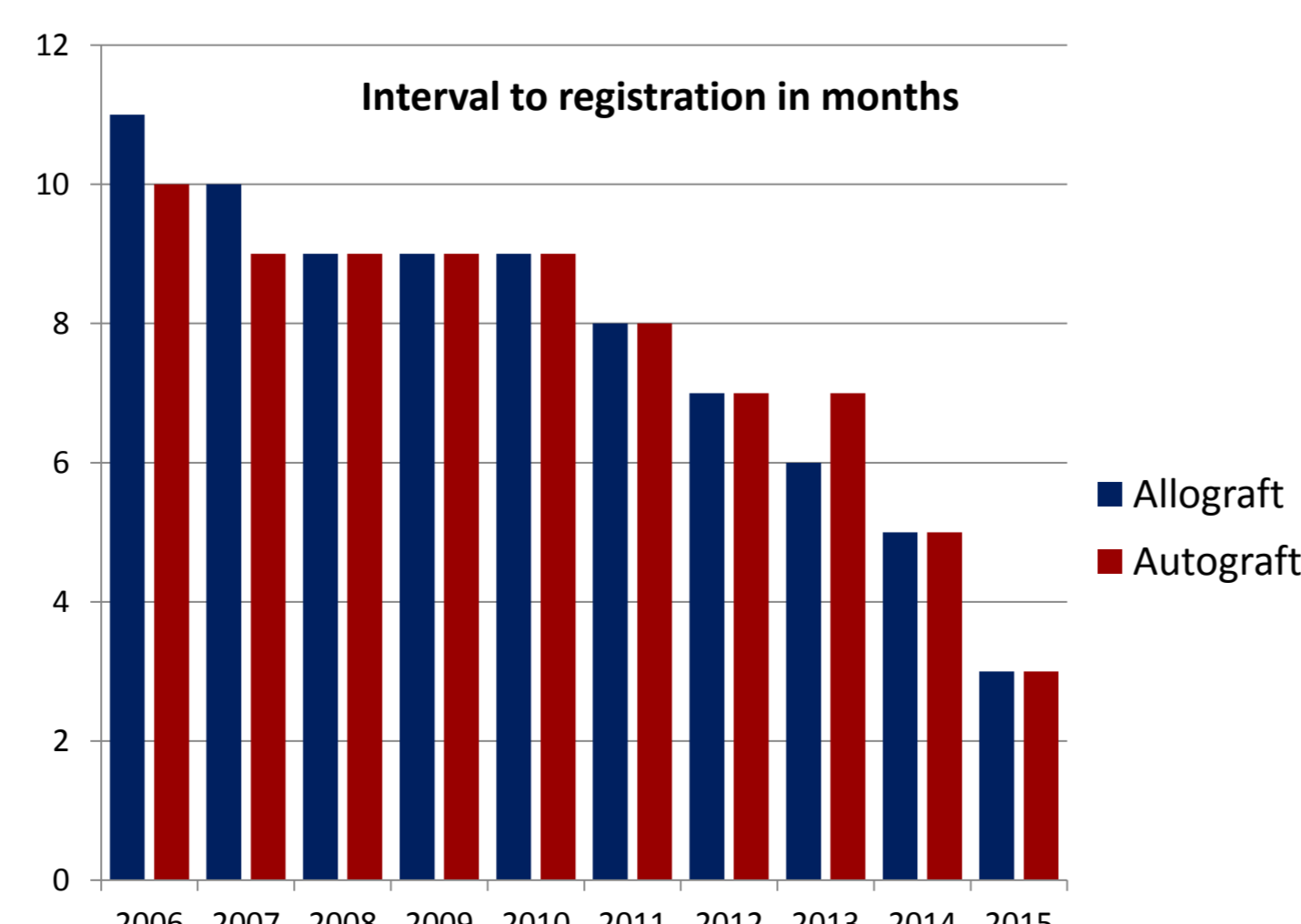
The "Other" Problem

The battle to reduce the number of drugs entered as "other" continues as unfortunately the problem persists and even increased slightly in 2015. Please remember to enter all drugs using the given codes & avoid using "Other". Drugs that are not properly coded create substantial difficulties when analysing data for studies.



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



2015 - conclusions

- 2015 was a busy year for the EBMT Registry! With **your help** we have:-
- Implemented the upgrade to ProMISe-3 which offers: improved security of EBMT data; a secure facility for exchanging files and downloads, and automated password renewal.
- Launched the first ProMISe Training Videos on the EBMT website
- Implemented the full Lymphoma WHO classification into the Registry database
- Worked with the Registry Working Group to revise EBMT data collection procedures and improve data quality by introducing important changes to the MED-A data collection form.
- Introduced and piloted the new Med-A form →

New Med-A up and running

We launched the new Med-A in the Registry database in December 2015 (see separate poster)

You can find **further information** in the [Helpdesk](#) section of our website.

We are here to help! Please contact us on registryhelpdesk@ebmt.org