



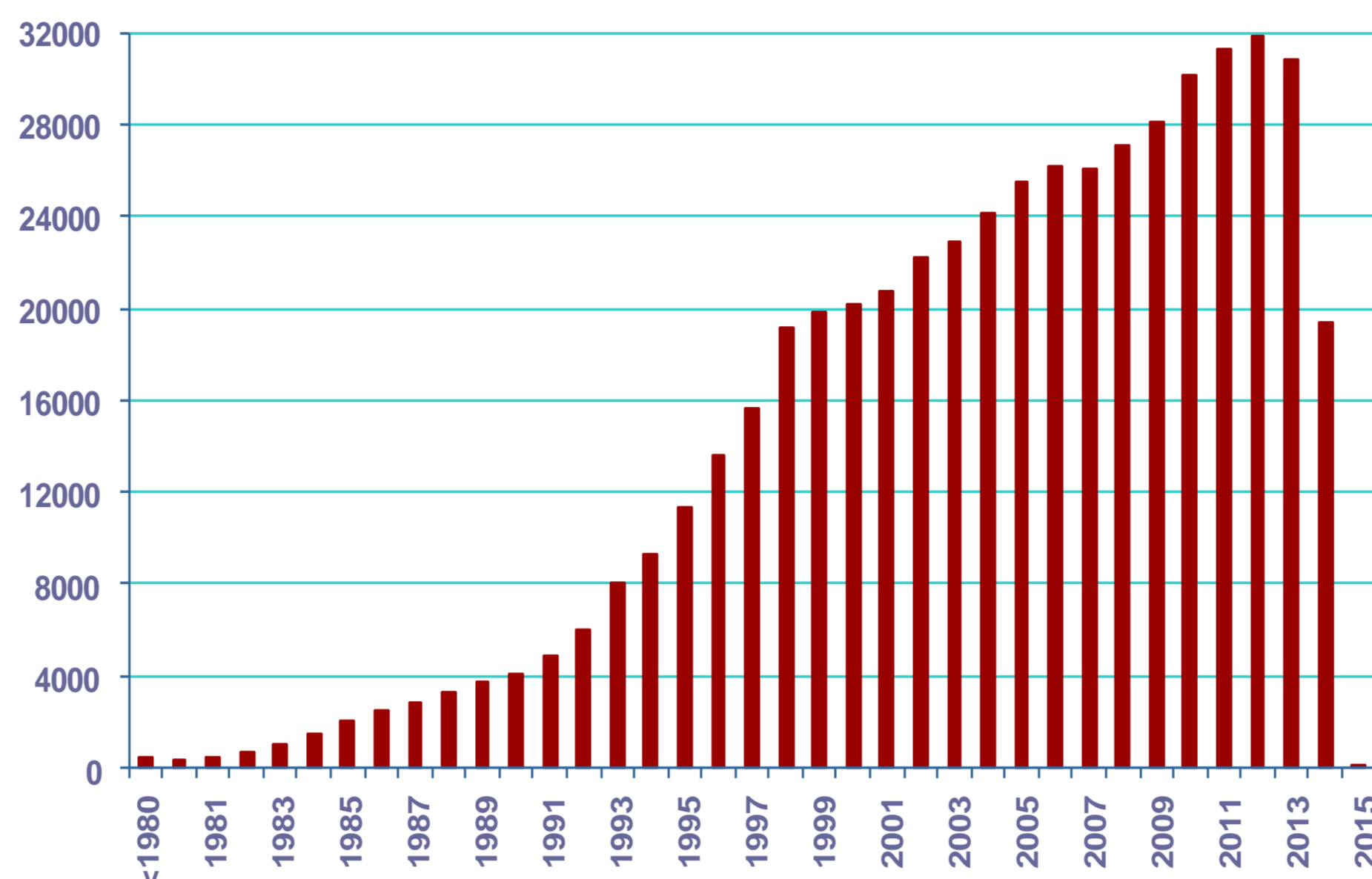
The EBMT Registry - Data

EBMT Registry Office, London

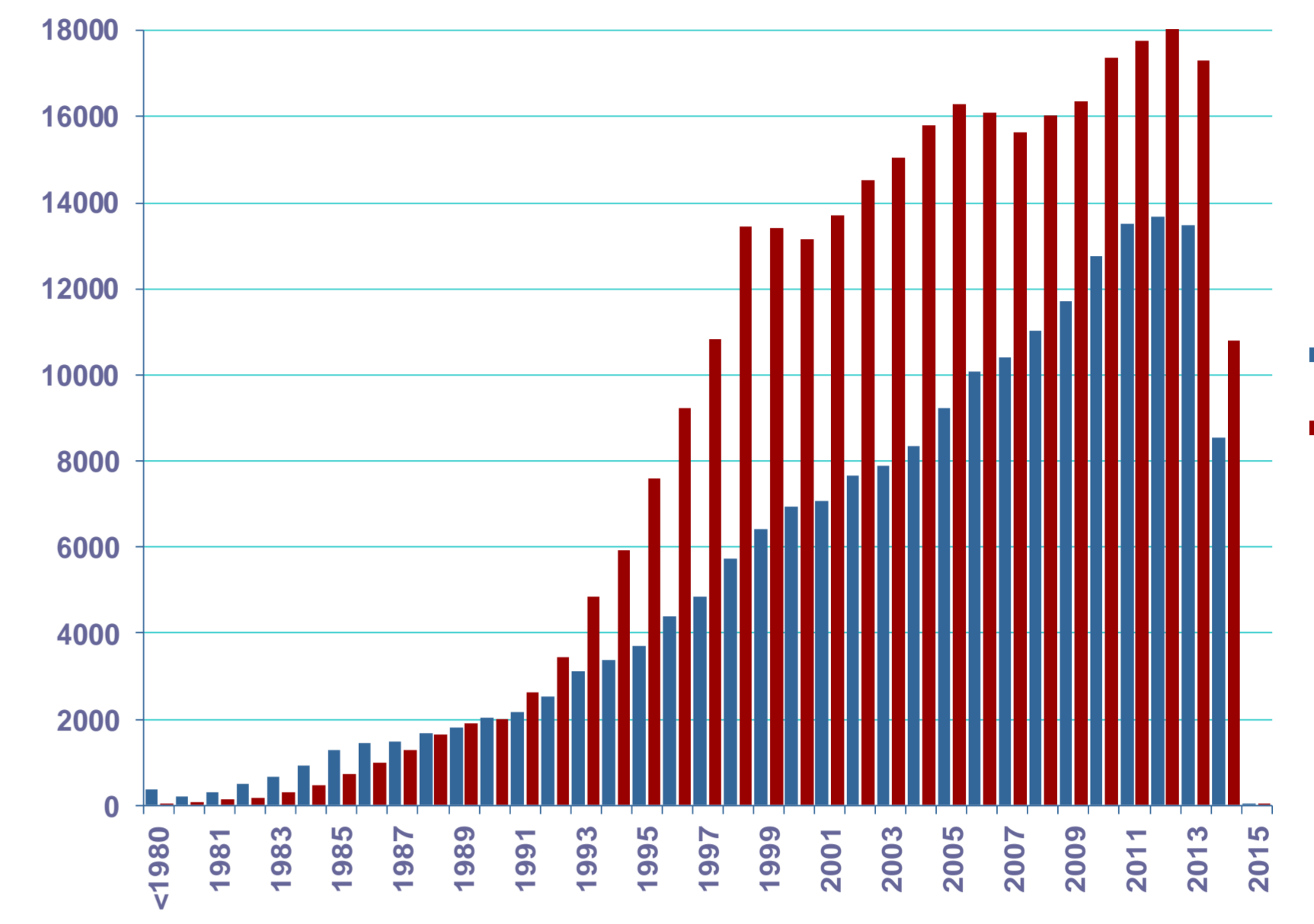
EBMT Registry

Disease	Patients	Transplants
Acute leukaemias: AML	64,257	70,472
Acute leukaemias: ALL	40,179	43,303
Acute leukaemias: other/unknown	2,317	2,597
Chronic leukaemias: CML	20,705	22,309
Chronic leukaemias: CLL	6,221	6,866
Chronic leukaemias: other/unknown	764	847
Lymphomas: NHL	85,669	95,242
Lymphomas: Hodgkins	29,585	34,095
Lymphomas: other/unknown	1,646	1,752
Multiple myeloma/Plasma cell disorders	94,163	127,573
Solid tumours	38,857	52,312
Myelodysplastic/myeloproliferative	28,610	32,225
BM Failure syndromes including AA	10,585	11,656
Primary immune deficiency	4,416	5,016
Inborn errors: other / unspecified	2,016	2,270
Histiocytic	1,141	1,255
Autoimmune diseases	1,793	1,842
Haemoglobinopathies	5,114	5,385
Other/unknown	185	212
Total	438,223	517,229

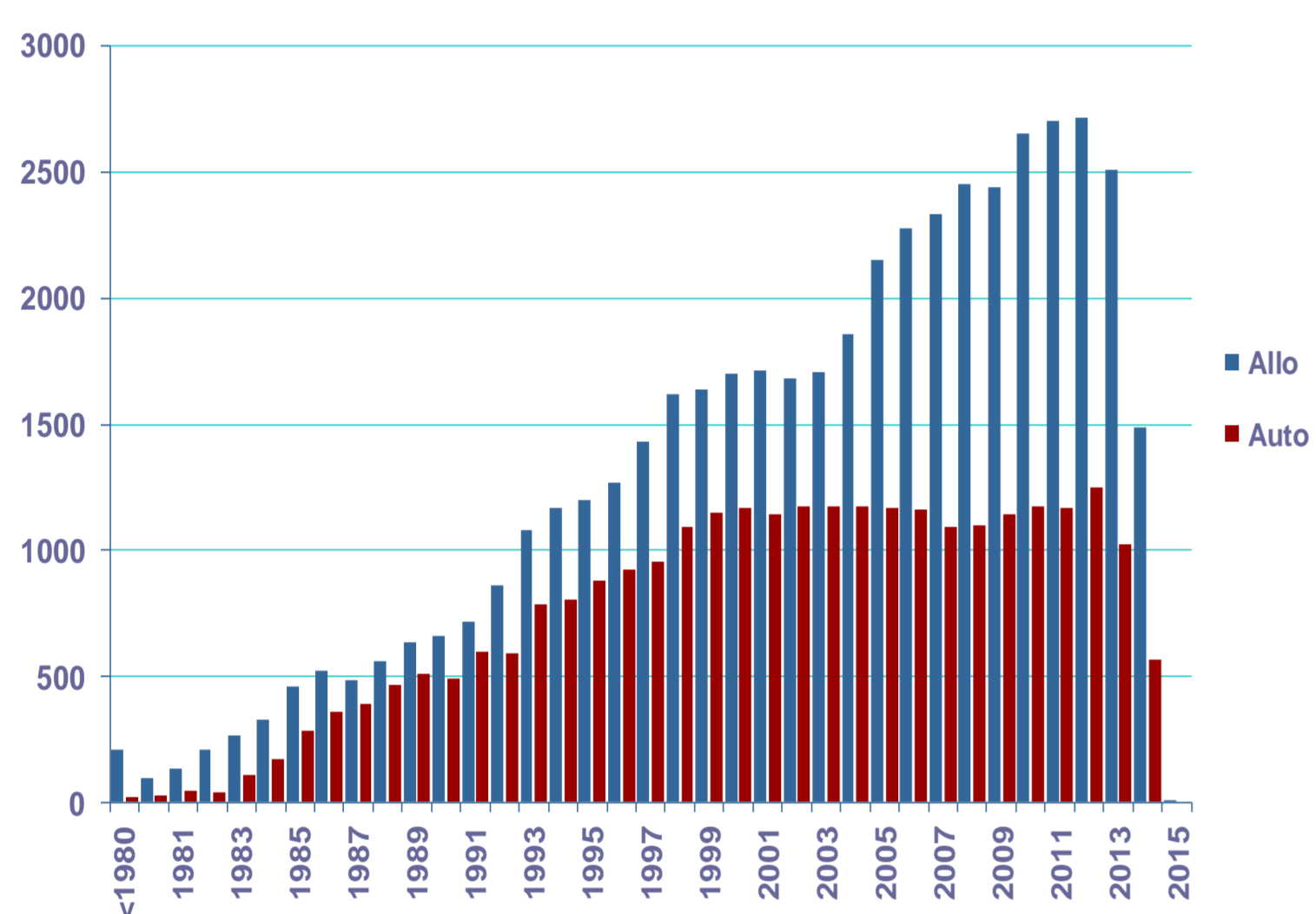
Number of transplants by year



Type of transplant by year



Paediatric transplants by year



Follow up: Avoiding bias

Follow up is one of the most important parts of our Registry, allowing researchers to isolate treatments that lead to a better quality of life, not only in the immediate aftermath of the transplant, but for decades later.

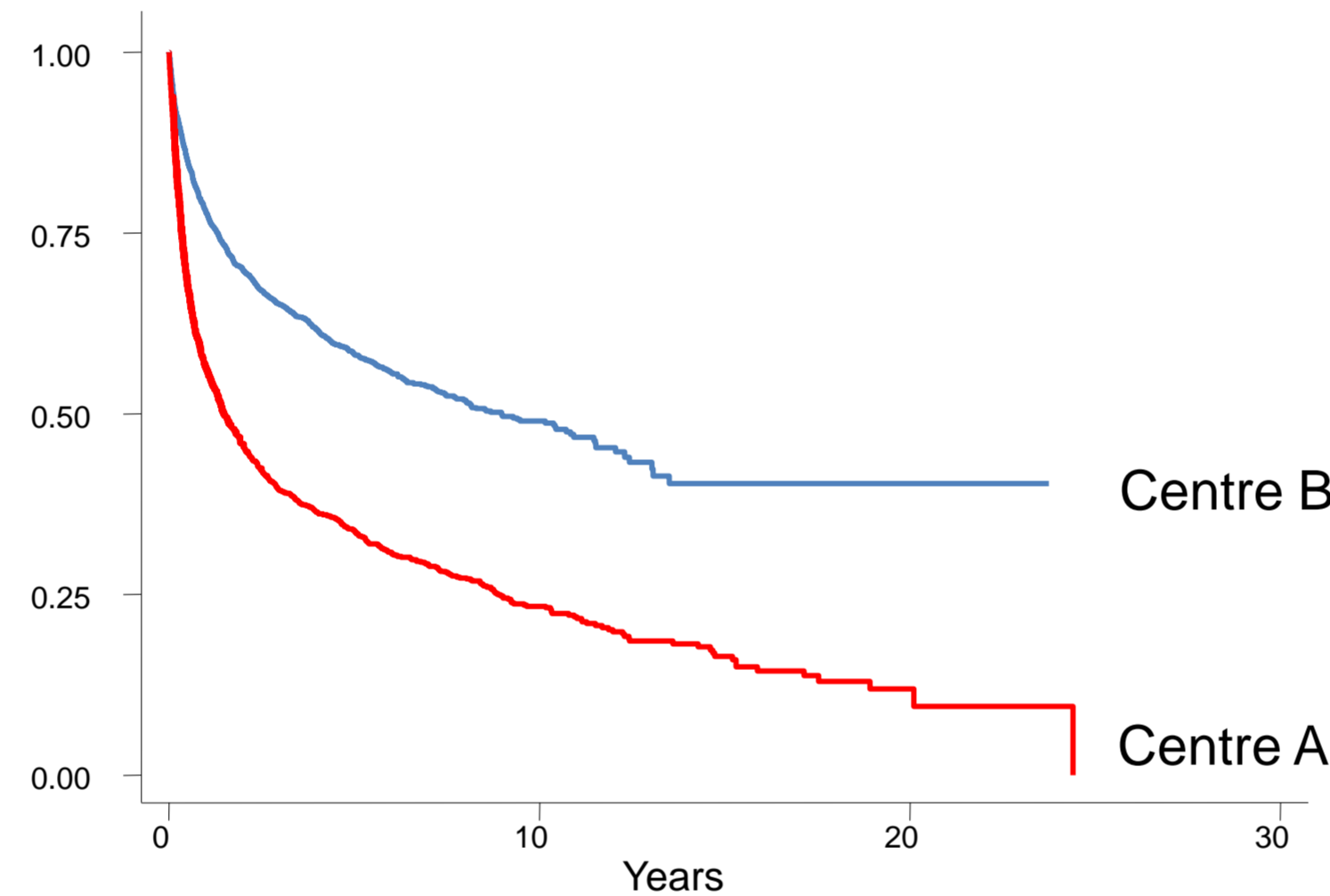
The length of follow up is crucial, but avoiding bias is also of great importance.

We show below some of the most common pitfalls when follow up is not performed in a systematic and continuous fashion.

NOTE: The overall survival curves are rough estimates, chosen for illustrative purposes only and convey no significant clinical information.

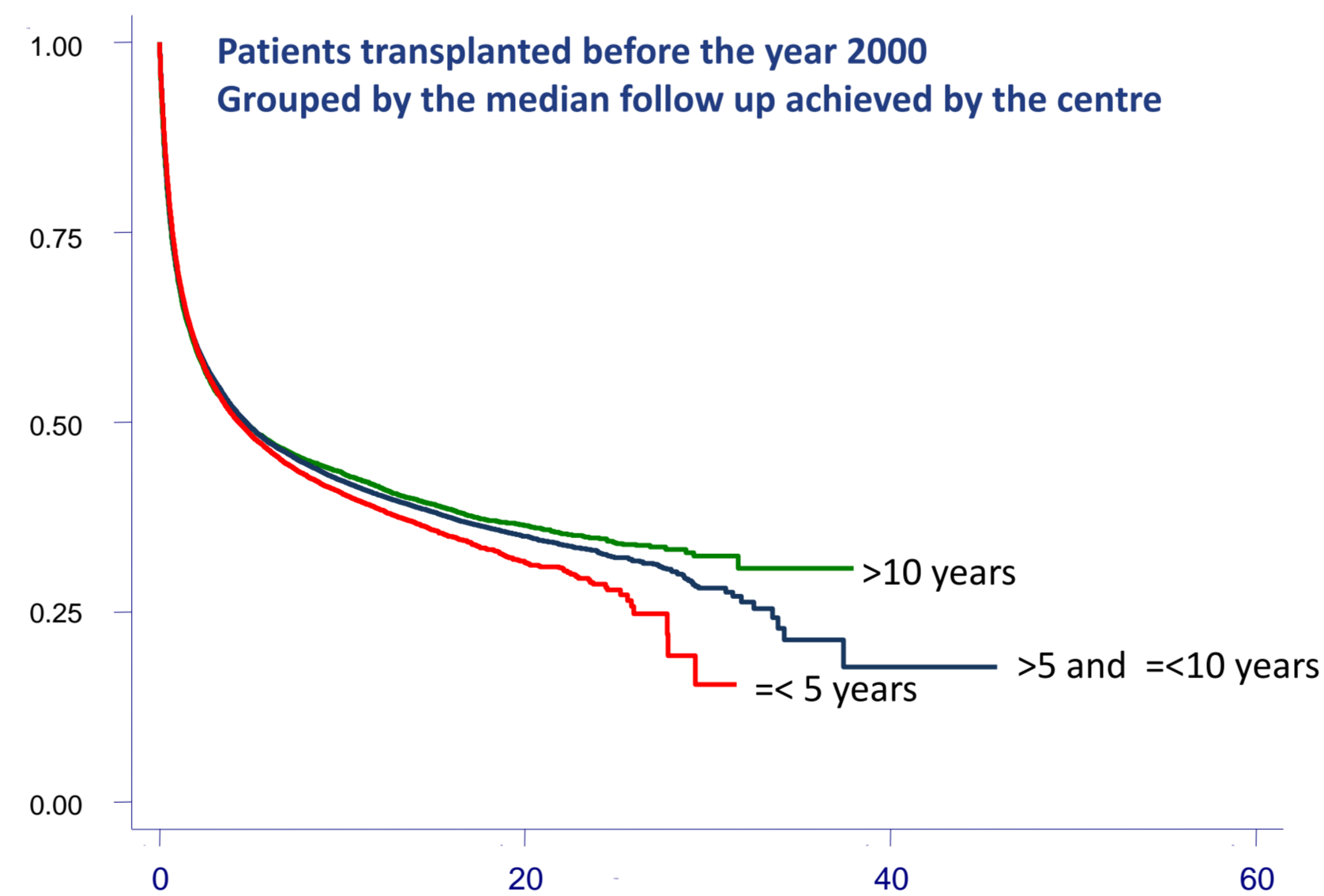
Preferential follow up

Centre A updates the follow up only when "something happens", this includes death
Centre B systematically updates all patients



Length of follow up

Centres that have the same outcome may look worse when follow up is shorter



Registration Completeness

- We aim to obtain 100% HSCT registrations from our members
- A comparison with the Activity Survey, conducted independently from the Registry, shows that this is not the case
- The reasons are twofold:
 - Non reporting centres
 - Centres submitting less HSCT than they perform
- The decrease in reporting, compared to the Activity Survey, is worrying and may reflect the increasing data management burden of the centres
- An additional motive may have been some centres waiting for the implementation of the new system before sending their data managers for training

Average of the % of HSCT registered by each centre compared to Activity Survey



Internet data entry

WHO IS ENTERING OUR DATA?

Access through ProMISe continued during 2014:

520 users from 393 centres have accessed the database for entering at least 5 registrations during 2014

New registrations entered through ProMISe in 2014:

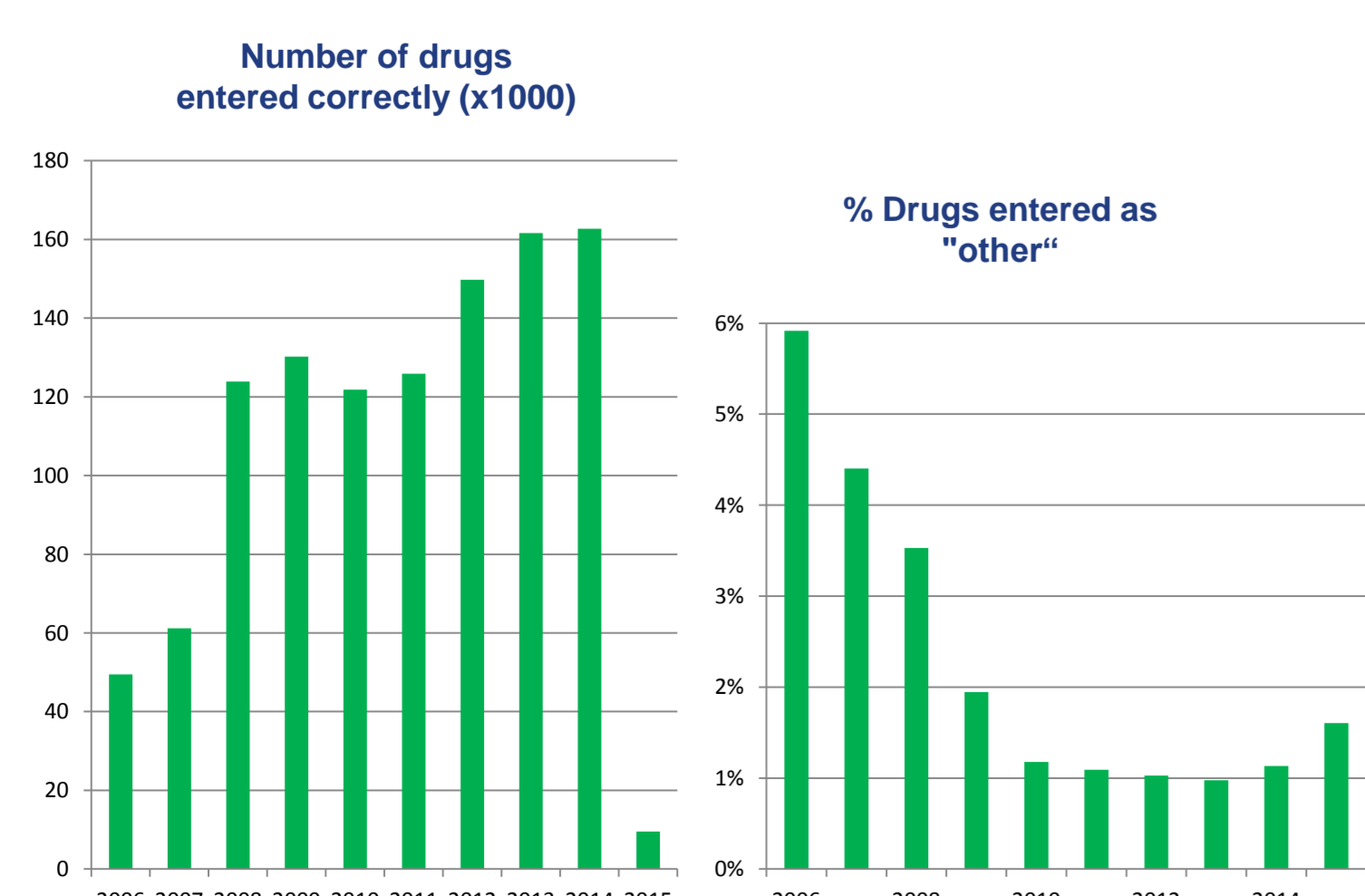
	Patients	Transplants
Centres	24916	28057
National Registries	4352	5204
EBMT	3727	4338
Total	32995	37599

The "Other" Problem

Unfortunately, the trend to enter drugs correctly labelled rather than as "other" seems to have stalled.

Most drugs are coded in the database BUT all drugs are known by different names in different countries or contexts.

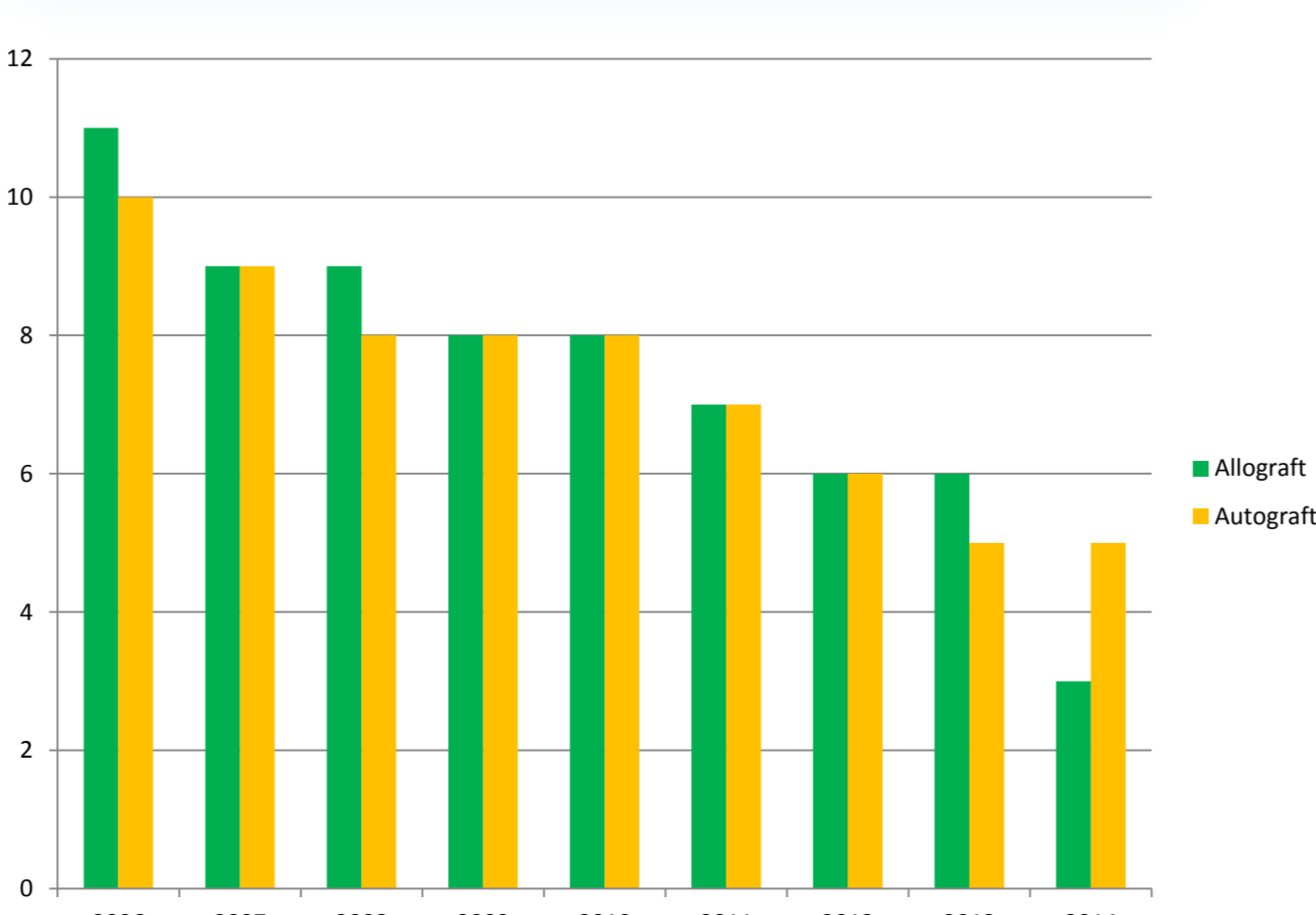
ALWAYS CHECK THE HELP FILES IF YOU CANNOT FIND YOUR DRUG



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

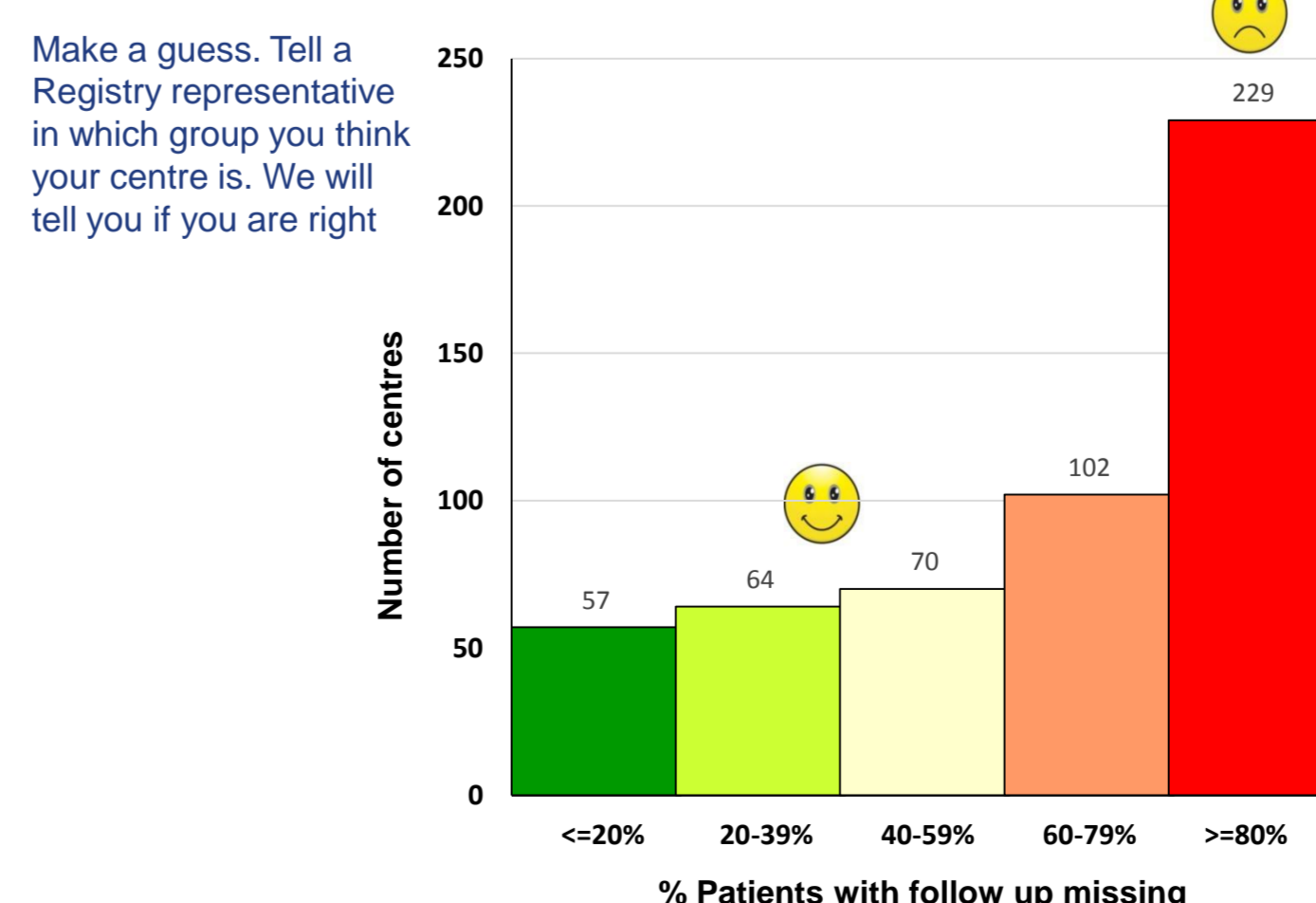
Months from date of HSCT to HSCT registration



Follow up: a challenge for all

WHERE IS YOUR CENTRE?

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



*Completeness is defined according to the following parameters:

- HSCT date less than 10 years ago -> follow up due every year;
- HSCT date between 10 and 20 years ago -> follow up due every 2 years;
- HSCT date more than 20 years ago -> follow up due every 5 years

2014 - conclusions

Despite the difficulties generated by the suspension of the Registry Upgrade project, it is business as usual for the Registry.

A cause of concern is the small but noticeable reduction in the number of transplants reported as compared to the Activity Survey.

A substantial push to improve Data Quality was sustained during the year with good results. Centres reacted positively to these initiatives and there has been a flow of exchanges between the data managers of the centres and the Registry which has resulted in improved and more complete data. We thank all of you who are reading this for positively responding to this initiative.

At the end of 2014, we initiated another push for follow up data & contacted 418 centres regarding patients whose follow up had not been reported for at least 5 years. By the beginning of February 2015, 13% of centres had updated those follow ups. We appreciate all the work they have been doing. The follow up challenge continues.