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Aim

To improve the quality of the data that is currently available in the EBMT database, improve the follow up data and reduce future work load for centres.

Strategy

In March 2017 excel files were send out with all Bone Marrow Failure patients per centre that are prefilled with the data currently available in the EBMT database. Centres were asked to check the available data and provide missing data. Importantly this will include information about pretreatment regimen, engraftment, graft versus host disease, relapse and last follow-up.

Status

358 centres were contacted. In February 2018 61 centres returned a completed Excel file. Another 50 centres agreed to send their patient data. In January a new reminder was send to all centres. Data collection is still ongoing and will be closed mid June 2018.



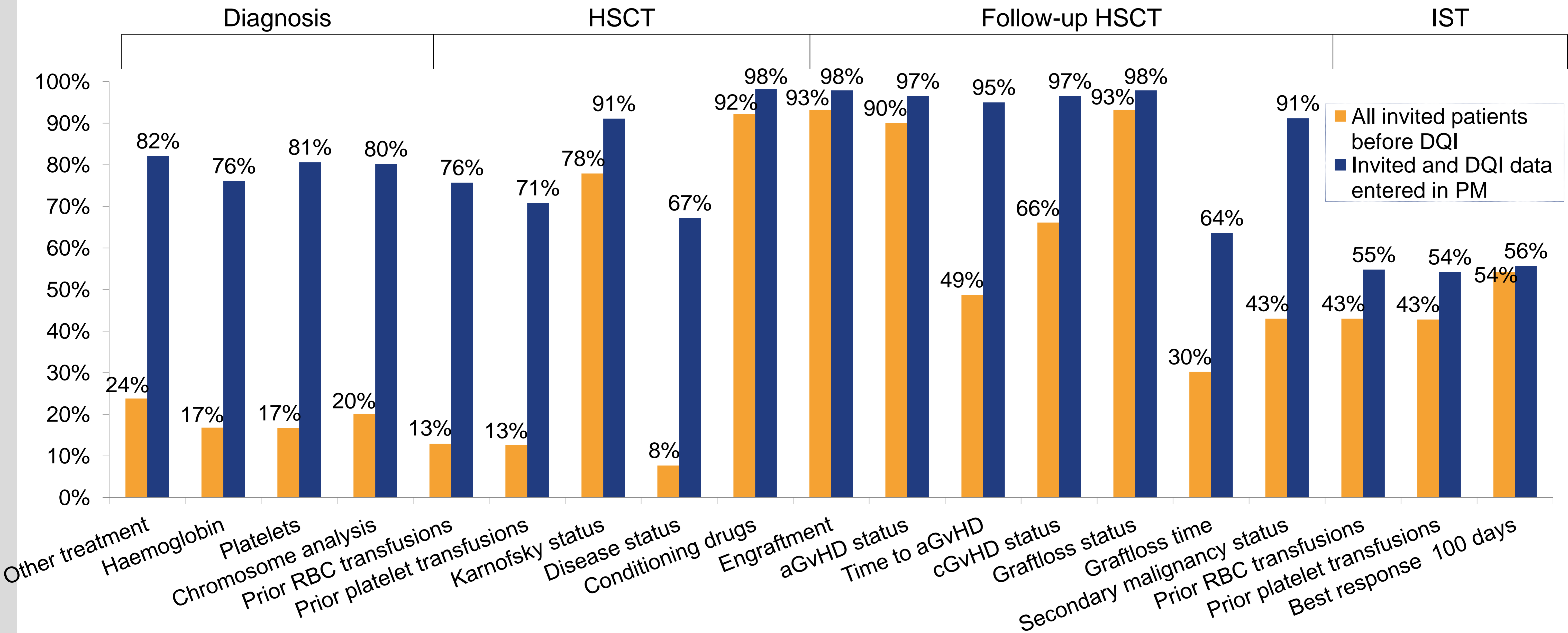
Deadline data collection: June 15<sup>th</sup>, 2018



Country	Australia	Belgium	Brazil	China	Colombia	Finland	France	Germany	Greece	India	Israel	Italy	Malaysia	Netherlands	Poland	Romania	Russia	Saudi Arabia	Serbia	Singapore	Spain	Sweden	Switzerland	Turkey	UK	Grand Total
Sites participating	1	7	1	1	1	3	14	15	1	1	1	16	1	3	1	3	2	2	1	1	9	3	2	9	12	111
Add. patients expected		71			2		206	71	8	6	6	265	2			1		195	9	3	79	57	106	155	216	1458
Sites data received	1	3	1	1		3	10	9				8		3	1	2	2	1			4	1		4	7	61
Patients data received	8	52	6	66		29	137	122				68		122	14	18	143	111			34	27		49	142	1148

Available data

Mid January there was (good quality) data was entered in our data base of 1114 patients (60 centres). 1046 first transplants, 485 first immunosuppressive treatments. The figure below shows the percentage of available data for some key variables for all invited patients (orange bars) and for all patients completed by this DQI (blue bars) at different time points, at diagnosis, at HSCT, at follow-up and at the end of the graph the availability for immunosuppressive treatments.



HSCT	Before invitation Pts alive (n=5705)	Invited and DQI data entered in PM Pts alive (n=837)	Immunosuppression only	Before invitation Pts alive (n=1421)	Invited and DQI data entered in PM Pts alive (n=340)
Length of follow-up (months) – median + range	22.08 (0-299.40)	45.04 (0-319.01)		57.60 (0-458.78)	98.61 (4.83-363.30)

CONTACT

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