



EBMT Registry

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Introduction

The EBMT Registry, as successor of EBMT's old database ProMiSe, was released on August 24, 2023 as a minimal viable product.

Since go-live 1.5 ago, there have been 16 releases with new features, improvements and bug fixes to enhance user experience. The biggest milestones of 2024 were the release of the EBMT Registry's analytical tool, **MicroStrategy**, and the **Study Manager Tool**. For 2025, more releases are planned.

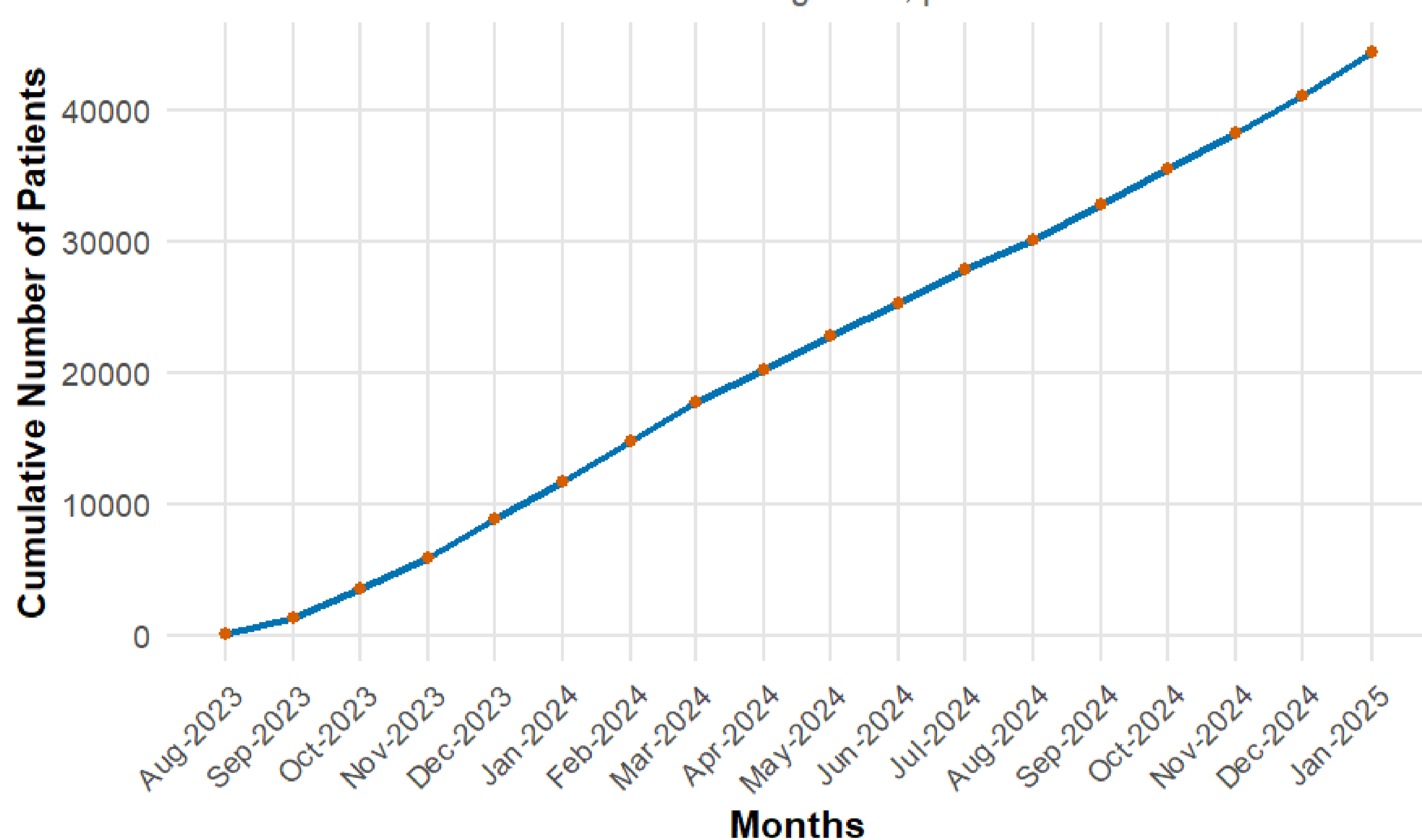
The release of the core dataset version 2 forms was another highlight of 2024. The core dataset is mandatory for all EBMT members to complete. Version 2 forms have been updated with the latest WHO classifications, diagnosis markers and complications post HCT and CAR-T.

Next to this, the extended dataset was released in 2024. The extended dataset consists of optional questions that can be completed next to the core items. The extended dataset collects, for example, haematological values at diagnosis, treatment for steroid-refractory graft versus host disease and details about infection surveillance.

The EBMT Registry in data

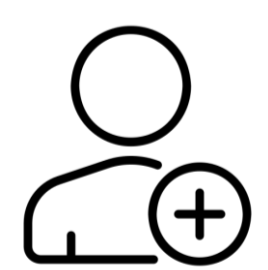
Cumulative Number of Newly Registered Patients

After ProMiSe migration, per month



Data Source: EBMT Registry

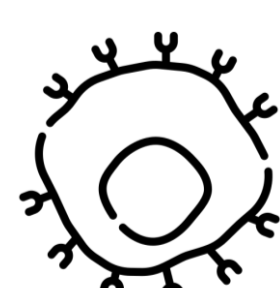
Since August 24, 2023... *



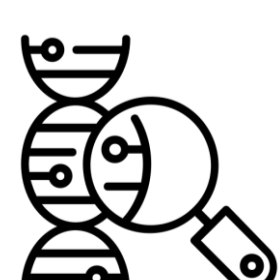
86,329 new patients added



21,459 new allogeneic HCT registrations
25,095 new autologous HCT registrations

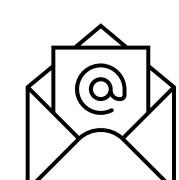


6,794 new cellular therapy registrations
(including CAR-T)



37 new gene therapy registrations

*Until February 1, 2025

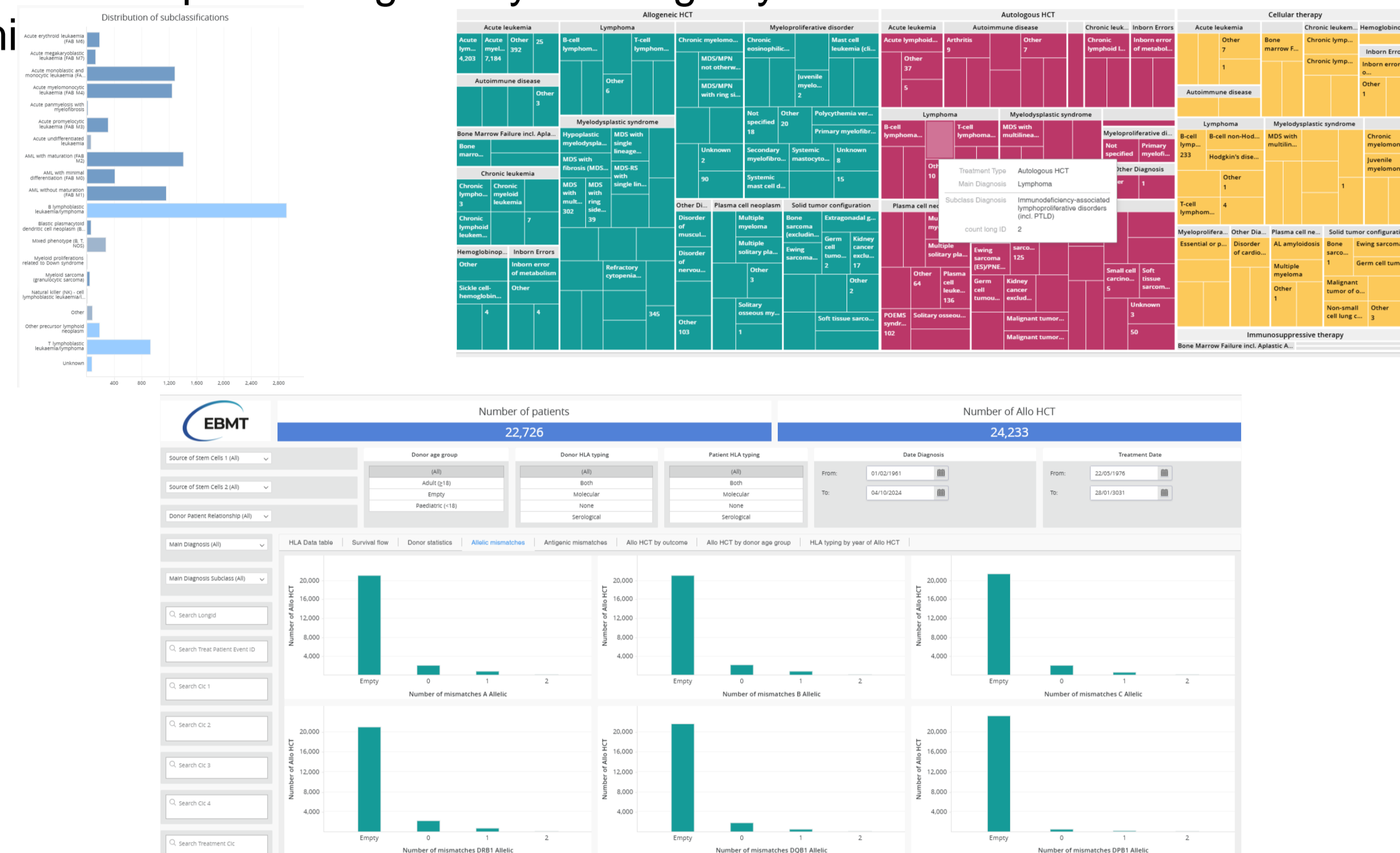


registryhelpdesk@ebmt.org

Analytical tool

The EBMT Registry is a data capture tool and does not have a native section to export and analyse data. This gap is bridged **via MicroStrategy Library**.

EBMT members can enter the EBMT Registry and access a library full of different reports designed by the Registry team with the user's needs in mind.



Above: screenshots from a report in the MicroStrategy library

EBMT Study Manager Tool

The past year EBMT Registry team, together with the EBMT Registry developers and representatives of the EBMT Study Units, have worked on an extra tool to perform studies requiring additional data collection within the EBMT Registry application.

The Study Manager tool will assist working parties to collect data that is not part of the core or extended dataset and will offer hospitals a safe and user-friendly environment to report study specific data. Pilot studies have started in Q1 of 2025, and evaluation moments are planned in Q2.

The Registry team hopes that the Study Manager tool will increase EBMT's efficiency in performing research to save and improve the lives of patients with blood-related disorders.

Study number	Stage	Short title	Study type	Principal investigator	Lead WP	Days until deadline	Clean	Submits	Added	Distributed	Created
893873	4	Test study 2	retrospective	Karina Lorenzo	Solid tumours	100	0	0	0	/	2025-02-21
893873	3	Test study 2	retrospective	Karina Lorenzo	Solid tumours	140	1020	1020	2001	2025-02-20	2025-02-17
CSU_0102	4	CSU_Test study	prospective	Maria Smith	Cell therapy & Immunobiology	190	0	17	17	2025-02-20	2025-02-20
1234	3	Test study 1234	retrospective	Name Summe	Autoimmune diseases	19	301	302	330	2025-02-13	2025-02-13
1010102	4	Test study 1	retrospective	Peter Gonzalo	Bone marrow failures (SAA)	(Study ended)	202	202	213	2025-02-30	2025-01-30

Above: screenshots from the Study Manager Tool

GOING FORWARD

In the coming year, the Registry team will put emphasis on providing more analysis-ready data files for hospitals, national registries and other stakeholders. To reach this goal, the Registry team will finalise the mappings of the extended dataset to the OMOP common data model, spend more time on data quality assurance and actively reach out to key users to explore their data needs.

The Registry team aims to play a bigger role in EBMT's scientific output by exploring options to share their knowledge about managing one of Europe's biggest medical databases.

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