



## Breadcrumb

1. Home

# Entity Print



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### Registry Upgrade

In 2021 the Registry had to make switch in approach regarding the Registry Upgrade project. We ran the Flash project to identify a new vendor for the future Registry platform. We did a PoC (proof of concept project) with a selection of vendors to test their ability to understand our needs, communicate effectively and propose a feasible solution to achieve a new Registry platform ready for the end of 2022. We

identified the new vendor. Together with the new vendor we started the workshops to define the detailed EBMT requirements. We invited to the workshops, different stakeholders such as centre data managers, national registries and EBMT staff. The project is now in full force and we are confident that we will deliver a new Registry by the end of 2022.

## Castor Database

Since ProMISe is reaching the last stage of its cycle and its functionality is not able to adapt to the necessities of the new forms, an alternative method for data collection on cellular therapy was necessary. As a temporary solution EBMT decided to use Castor EDC for this purpose. Castor EDC is an electronic data capture tool focused on user friendliness and simplicity which translates in a reduction of the time spent on data entry tasks. In 2021 the Registry team managed to finish all preparative steps for the importing of data into Castor in 2022. Thanks to this effort, during 2022 there will be a new system in place to store the Cellular therapy data.

## EDHEN Project

In June 2021 the Registry won a grant to participate in the EHDEN project. After a selection process, the company EdenceHealth was selected to help the registry with the effort of migrating to a standardized data model (OMOP CDM). These efforts started in October 2021 and will continue until (approximately) July 2022.

## CRM Project

The Registry has been greatly involved with the CRM Project. We have successfully developed, collaborated and designed the Data Modelling, Data Migration, Testing, Report design and Data Cleaning-Audit. As a result, we have managed to upload and create 18,190 records of Registry-Membership related information to the CRM.

## Registry Resource

In 2021 we said goodbye to 6 members of staff who had worked for the Registry for a number of years. We also welcomed 7 new members of staff. We continue to recruit for more people to ensure that we are able to deliver our normal services and also provide the Registry team with more hands and expertise in order to manage the many challenges in the year ahead.

## Membership Integration

The Membership team is now an integral part of the Registry, and Membership activities are overseen by senior Registry staff.

## Data Management Activities

Registry staff have been successfully carrying out the following activities during 2021:

1. Data entry, cleaning, retrieval, storage and deletion/destruction
2. Patient record merging
3. Data security, backup and recovery
4. Centre and User management and data access
5. Data transfer, sharing and exchange
6. Data report running
7. Data management support to EBMT Members
8. Helpdesk services
9. Membership services

## User Management

User Management has been a daily activity at the Registry in 2021. **400** Data Entry and Data Download User accounts were created and approximately **109** Data entry User accounts were deactivated by Registry staff in 2021.

## Centre Management

Centre Management has been a daily activity at the Registry in 2021. A total of **34** new Centres were created along with **3** new virtual Registries.

## Data Quality Activities

Registry staff have been successfully carrying out the following activities during 2021:

1. Castor database testing and validation
2. Data Collection Form (MedAB and Cellular Therapy) and Manual/Help file development/review/revision and management

3. Registry database instruction development, review and revision
4. Registry SOP/Standard Form revision
5. EBMT Registry website maintenance
6. Training and education
7. Support to EBMT members on data quality activities
8. Data Quality Report running and data cleaning management
9. Benchmarking

## Helpdesk

The Registry Helpdesk was the busiest it has ever been in 2021. Approximately **7,500** emails were sent by the Helpdesk to EBMT Members, EBMT staff, EBMT structures and third parties for EBMT Registry purposes in order to provide an effective Helpdesk service. The abovementioned figure does not include single emails sent to multiple recipients in 2021 for Registry purposes.

## Training

During 2021 no live training was delivered by Registry staff due to staff changes and restrictions related to the pandemic. Instead a number of pre-recorded training videos and written instructions on a variety of ProMISe-related data entry topics were published on the EBMT Registry webpages.

## Educational Sessions

A total of **15** online Educational sessions were arranged by the EBMT Registry during 2021. The **9** sessions in March 2021 attracted a total of **118** attendees and a total of **2,048** unique views. The **6** sessions in November 2021 attracted a total of **225** attendees. The feedback received for educational sessions arranged by Registry staff during 2021 has been positive.

## Membership

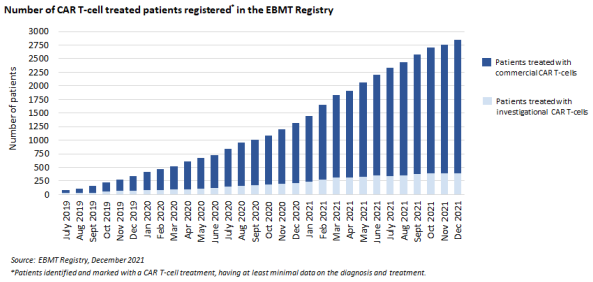
Approximately 2,700 emails were sent by the Membership assistant to EBMT Members, EBMT staff, EBMT structures and third parties for EBMT Registry purposes. The above-mentioned figure does not include single emails sent to multiple recipients in 2021 for Registry purposes.

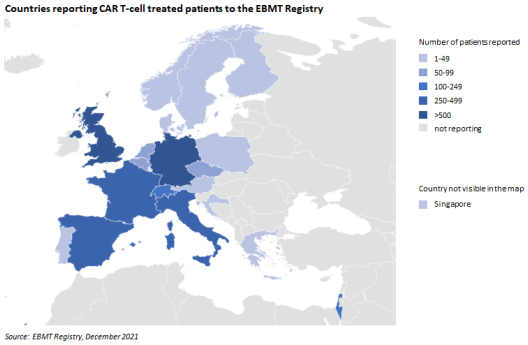
## New members

The application for new members has been a daily activity at the Membership in 2021.

We have successfully processed the membership applications of 34 centres and 44 individuals. There were also 17 centres reactivated to full membership.

# New Registrations for Cellular Therapy in 2021






Per Ljungman
REGISTRY COMMITTEE CHAIR
Sweden

# Registry Committee

The registry committee’s work during 2021 has been heavily concentrated on the upgrade of the EBMT registry. In the beginning of the year, the work was still concentrated to evaluate MACRO’s capability to meet EBMT’s requirement but at the same time, the registry staff evaluated other possibilities. After the formal decision of closing the MACRO project, the work has been concentrated on finding alternative solutions before the expected lifespan of ProMISe ends in the end of 2023. This work has been in three parts: 1) Finding a temporary ProMISe solution for the cellular

therapy registry. 2) Finding a new platform and vendor for the full registry. 3) In the latter part of the year to work on the content of the registry with the support from different EBMT offices, the statistics committee, and the working parties.

Another important activity has been the change of the definition’s subcommittee and replace it with an office-based solution with the support from the EBMT’s medical officer. Furthermore, the registry committee has been represented in the joint Task Force with other scientific societies in the field to work out updated and joint definitions to some important aspects of data collection such as graft failure, reduced intensity conditioning, AML relapse, and TMA.

The registry committee has also been an important part of the COVID-19 Task Force to gather and disseminate information about the impact of the pandemic on our patients and centers.

Finally, the registry has worked with education for example with the training course for data managers on the topic of cellular therapy.

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