

# EBMT Registry

## User manual for data editors and data viewers

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**EBMT Registry**

EBMT Clinical Research & Registry Department



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## New EBMT Registry

If not stated otherwise, in the context of the current manual, the term EBMT Registry is used to describe the web application created to collect, view, edit and retrieve data and associated with the application databases.

**IMPORTANT NOTE:** the EBMT Registry is in an ongoing development process. Screenshots in this manual might be slightly different from the live application. We strive for having the most up to date information.

### Objectives

#### Why do we need a new EBMT Registry?

The purpose of the EBMT Registry is to provide a pool of data to EBMT members to perform studies, assess epidemiological trends and ultimately improve patients' lives. The EBMT Registry underpins extensive European research that translates into changes in clinical practice, patient outcomes and care improvements. With constant development of the field, the data set to be collected changes, thus the database also needs to change and adapt to reflect the latest trends. In recent decades, EBMT members used services such as ProMISe (Project Manager Internet Server) and Castor to collect, enter and use information about their patients and donors. Unfortunately, these services could not accommodate all the needs of EBMT members, thus it was decided that a completely new EBMT Registry should be created.

EBMT involved their staff, software developers, analytical specialists, doctors, representatives of different medical centres, regional and national organisations and other stakeholders to ensure that the new EBMT Registry satisfies everyone's needs.

It is important to note that after extensive data quality checks, the data collected by EBMT since 1974 is to be securely transferred to the new EBMT Registry where it can be used by users within their access rights.

#### EBMT Registry database structure

The EBMT Registry is a flexible data entry web application, connected to a fast and responsive live application database, enabling users to enter and retrieve data. The application database is then connected to the analytical database where all the data is restructured and organised according to the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) (for more details on OMOP CDM please refer to <https://ohdsi.github.io/CommonDataModel/>).

Splitting the databases has allowed EBMT to separate and accommodate the data entry needs from the analytical needs. A lot of work has been done for the EBMT Registry database to acquire an internationally recognised standardised OMOP CDM analytical database which is patient-centric, flexible and extendable. This is deemed to cover EBMT requirements and will offer new possibilities in terms of data analysis to EBMT partners and stakeholders.

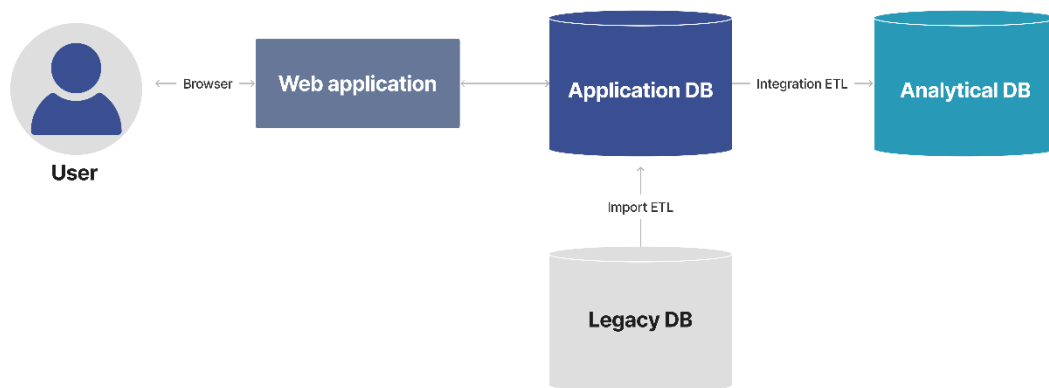


Image 1, schematic view of EBMT Registry application setup

EBMT legacy data (i.e. all the data collected by EBMT before the EBMT Registry went live) was extracted from ProMISe and Castor, transformed and loaded into the EBMT Registry application database and then, through integration ETL, also loaded to the analytical database. ETL is a type of data integration that refers to the three steps: extract, transform and load; it is used to organise data from multiple sources.

It is important to note that the EBMT Registry application database always reflects the latest state of data, which is then copied, transformed and transferred into the analytical database according to a predefined schedule (currently once per 24 hours), thus there is expected delay to have data changes reflected in the analytical database. Otherwise, the data is considered to be equivalent, only organised in two different ways: the application database is event-centric, and the analytical database is patient-centric.

The information shown via the user interface of the EBMT Registry is always the latest.

## Technical requirements and specifications

In order to access and work smoothly with the EBMT Registry, the users need to comply with the following technical requirements:

1. Computer with a stable internet connection. The EBMT Registry is a web-based application and requires access to the internet to load web pages.
2. Computer with a mouse, touchpad, touchscreen or similar device to navigate around the screen interface.
3. One of the following supported internet browsers:
  - **Google Chrome:** the latest two versions of the browser on all operating systems.
  - **Mozilla Firefox:** the latest two versions of the browser on all operating systems.
  - **Microsoft Edge:** the latest two versions of the browser on Windows operating system.
  - **Safari:** the latest two versions of the browser on iOS and macOS operating systems.

It is expected that other browsers also work correctly with the EBMT Registry, but it was not possible to perform sufficient testing and guarantee its high performance.

4. A screen that has a resolution of 1080p or higher. Screens with lower resolution were not tested, thus the correct layout of the web pages cannot be guaranteed.
5. A personal work email address to which the user has access. Shared emails must not be used.
6. Authenticator application: it can be MFA for smartphone, tablet or computer. (see [Multi-factor authentication](#)).

## Multi-factor authentication

Multi-factor authentication (MFA) with an authenticator application is mandatory to enter the EBMT Registry. It is a security feature that requires users to provide multiple forms of identification to access EBMT Registry and patients/donors information. One of the MFA applications must be installed on the user's computer, tablet, or smartphone:

- Google authenticator;
- Twilio Authy (desktop app);
- Microsoft Authenticator;
- 1Password (desktop app);
- Symantec VIP Access app;
- LastPass Authenticator;
- 2FAS;
- Duo Mobile;
- Dashlane (desktop app);
- Bitwarden (desktop app);
- Authenticator App by 2Stable (app for iPhone, iPad, iPod, Apple Watch and Mac);
- Step Two;
- TOTP Authenticator (desktop app, this is a browser extension).

This means that this MFA device shall always be available and used when a user needs to [Sign in](#) to the EBMT Registry. If a MFA device becomes unavailable (e.g. lost, stolen, broken, or replaced by a new device), the user should contact the EBMT Registry Helpdesk by emailing [registryhelpdesk@ebmt.org](mailto:registryhelpdesk@ebmt.org) to [reset MFA settings](#) for this user.

## User session

It is essential to note that once a user signs in and enters the EBMT Registry, the user session remains active. For security reasons, the user session will expire automatically, and the user will be signed off after 20 minutes without activity. Termination of the user's session means that the user is signed out, and the sign-in page is shown on the screen.

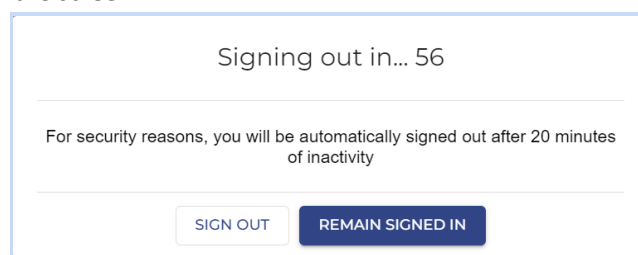


Image 2, Warning on automatic termination of user session due to inactivity

**Important:** EBMT Registry does have active termination of a user's session after 20 minutes of inactivity, it means that during that time, the information on the web page remains visible. Thus, users are strongly advised to use the [Sign out](#) process and lock the computer screen even for short periods of time to prevent unauthorised access to the data.

## Is there a transition period?

ProMISe and Castor, which have been the staple point so far, will be closed for data entry, and after a short timeout period, data entry to the EBMT Registry will be open. Nevertheless, for a limited period of



time (exact dates to be communicated to users in the EBMT Registry newsletter or other official communications), users will still be able to access ProMISe and/or Castor to view or extract previously entered data.

Complete migration of the database will happen in stages and will be finished post-go-live. This means that some data field values will not be migrated when going live, and up till then, affected data fields will be clearly marked (see more details [here](#)). Once migration is finished, users will be able to see all legacy data automatically.

Once the EBMT Registry is open, users can enter data for their patients and donors (reports on diagnosis, treatments, follow-ups, etc.), register new patients or donors, and use the system as described in the current Manual.

The EBMT Registry starts being used with its core and minimum functionality to ensure the data collection does not stop. In the meantime, the process of development will continue. The EBMT members and other involved stakeholders will be informed about new versions and additional functions once they are ready.

### Main changes compared to the previous systems

The EBMT Registry application is more user-friendly and flexible in terms of reflecting and adapting to the new requirements.

The EBMT Registry consists of two big registries: Patient registry and Donor outcome registry.

Patient data in the EBMT Registry is organised in a logical timeline, illustrating the date the diagnosis was stated, the treatment was carried out, the follow-up was done, etc. A patient record can have multiple event reports that are organised in chronological order.

Donor data in the EBMT Registry is now organised in the same way as the patient data; a donor record can have multiple event reports organised in chronological order.

As it was mentioned in previous sections, the EBMT Registry now has two databases: an application database and an analytical OMOP database. The OMOP database is a huge step and achievement as now the data in the EBMT Registry is organised in the globally recognised standardised format.

### Data ownership and protection

EBMT is strongly committed to protecting the privacy of personal data that we maintain about patients, donors, members and users of the EBMT Registry. The EBMT ensures that all personal data under its responsibility is processed according to the EU General Data Protection Regulation (GDPR).

For more information on Data Protection and Privacy, please refer to the EBMT website <https://www.ebmt.org/registry/data-privacy>.

### Audit trail

The Audit trail is an important feature of the EBMT Registry to track changes made to data of [patients](#) and [donors](#), users, [centres](#) and other [registered entities](#). All actions are registered in the audit trail. The Audit trail information is not available to users of any roles but for a minimal number of specialists from EBMT Registry. This section describes its general overview and setup.

The audit trail is implemented with two main concepts in the EBMT Registry:

1. The **audit trail entries** provide an explicit event log of initiated actions and the circumstances in which they took place (who did what and when).
2. The **version histories** provide a detailed history of data fields throughout its lifetime - what data was added/changed and why. Version histories cannot be used to back up or cancel changes. It is used purely for the trackability of actions.

Audit trail and version histories can be used separately or together.

This division was established to satisfy the regulatory requirements without impacting performance or compromising audit trail readability. Here below is a short summary of its specifications:

- Version histories contain data points which may describe sensitive data that is not to be shared outside of exceptional circumstances;
- Version histories represent data entities in their entirety, which makes it simpler to reconstruct what has happened after the change;
- The audit trail entries focus on what actions took place and can just refer to the new version of a data field that was created as a result;
- The audit trail entries do not contain sensitive material and can therefore be more easily exported or even shared if required.

Note: Further improvements are planned to be done to the Audit trail access post-go-live.

## Wiki

The EBMT Registry will include a link to the specifically designed Wiki platform.

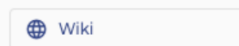


Image 3, the Wiki icon

Wiki is a document platform where EBMT Registry users can find useful information they might need in the process of data entry or interaction with the system, such as:

- EBMT Registry user manual for data viewer and data editor;
- Reference to Data collection forms manual;
- FAQ: frequently asked questions.

Users can search for the topics through the content, keywords or tags.

## Patients and Donors

### Patient

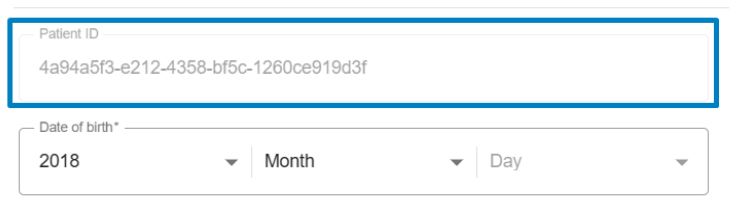
A **Patient** is a person who received a haematopoietic cell transplantation (HCT) procedure; an individual with bone marrow failures receiving immunosuppressive therapies; and/or a person receiving cellular therapy.

The **EBMT Patient Registry** collects pseudonymised clinical data of consenting patients, including aspects of the diagnosis and disease, first-line treatments, HCT or cellular therapy-associated procedures, transplant type, donor type, stem cell source, complications and outcome. Patients are followed up indefinitely or as defined by EBMT (see Data collection forms manuals). Once registered, patients may only be deleted by the Administrator of the system if they withdraw their consent and specifically request their data to be removed from the EBMT Registry (see [Edit Patient consent](#)).

Every Patient in the EBMT Registry is registered as a unique individual and assigned with:

**EBMT patient ID** - is a unique patient identifier in the EBMT Registry that is generated automatically by the system in GUID / UUID format at the moment of patient registration in the EBMT Registry. It is a long code that contains letters (English alphabetic characters: a to z) and numbers (Arabic numerals: 0 to 9) for internal system use. It is not expected that users need to use it while interacting with EBMT Registry, but in case needed, the EBMT patient ID is shown in the [Patient menu](#) Edit patient details section.

Edit patient



The screenshot shows a web form titled "Edit patient". It contains two main input fields. The first is a text box labeled "Patient ID" containing the long alphanumeric string "4a94a5f3-e212-4358-bf5c-1260ce919d3f". The second is a date selection field labeled "Date of birth\*" with a dropdown menu showing "2018" and two other dropdown menus labeled "Month" and "Day".

Image 4, the long EBMT patient ID

**EBMT short patient ID** - shortened version of the EBMT patient ID for the convenience of the users to be used to find patients in the system. The EBMT short ID consists of the last seven digits of the EBMT patient ID.

**UPN** (unique patient number) - the number/code used by the transplant centre or other entity to uniquely identify this patient. The organisations that input patient data have their own internal patient identifiers that should be entered into the EBMT Registry and are used for the duplicate checks. The users can also use UPN in order to search for patients.

In case of an error or change of UPN number, users are not able to correct the UPN through the user interface. Users should contact EBMT Registry Helpdesk, providing all the details on the case to request such a change.

All patients in the EBMT Registry are **linked** to one or more centres. This means that centres have access to the patient data.

For the users' convenience, the EBMT Registry will still keep the record of ProMISe ID for patients who were registered in ProMISe system and later migrated into the EBMT Registry. However, this field is not relevant and will be empty for patients registered in the new EBMT Registry.

Every Patient is registered with some general data (see [Add Patient](#)) and associated medical events (see [Add new event](#)). More details on data collection are provided in the Data collection forms manuals. If a patient does not consent to share their data with EBMT, said Patient cannot be registered in the EBMT Registry, and only minimal data on performed treatment can be collected (see [Anonymous events](#)).

### Patient event

A patient event represents a significant occurrence related to a patient's medical condition. Every event in the EBMT Registry corresponds to a specific Data Collection Form. An event definition provides a way to document and track a patient's medical history over time, and it provides a comprehensive picture of the patient's health status and treatment progress or outcome.

### Patient event category

Since EBMT has a high number of patient events, they are grouped into the following **patient event categories**:

- **Diagnosis:** it includes forms for primary diagnosis that was an indication for the treatment and other non-indication diagnosis that may directly or indirectly influence the outcome of the treatment;
- **Treatment:** it includes treatment specific form Autologous HCT, Allogeneic HCT, Cellular therapy, IST, and Disease status at HCT/CT/IST;
- **Follow-up:** all follow-up (FU) forms, e.g. HCT Day 100 FU, HCT Annual and unscheduled FU, CT FU, etc.
- **Other:** study specific forms, etc.

Thus, every patient event contains a specific set of data (data fields) as per the corresponding Data Collection Form.

Some patient events also contain questions on donors and donated material, but this information is collected purely for the completeness of the specific Patient treatment and cannot be considered as donor registration (see [Donor outcome registry](#)).

When a new patient is being registered in the EBMT Registry, an [automated duplicate check](#) is performed: registration data of the new patient is compared to data of existing patients in the database. When a duplicate is suspected, the system warns the user and marks the new patient with a **tentative patient status**.

### Tentative patient

A Tentative patient is a temporary status automatically assigned to the patient by the system to mark that it is a possible duplicate of an existing patient earlier registered in the system. Only an [Administrator](#) can remove tentative status from the patient record after a more comprehensive and thorough evaluation.

An Administrator will revise the tentative patient record and follow up with the centre on such cases if needed. If the new patient is confirmed to be a duplicate of an existing one - the new patient will be deleted from the system. If it is confirmed that this is a unique patient, the Administrator will remove the tentative patient status, and the patient will then appear as a regular patient in the system.

Tentative patient status is assigned by the system to *possible* duplicates while comparing patient birthdate, initials, sex at birth, blood group, and rhesus factor to the data of existing patients (registered by any centre). If the existing and the new patient have the same UPN within the same centre, this is not

considered as a possible duplicate but an exact duplicate, thus the system will not allow registration of a duplicate showing the corresponding error (see [Duplicate check](#)).

## Donor

A **Donor** is a person who is the source of cells or tissue for allogeneic HCT or cellular therapy product.

**EBMT Donor outcome registry** is a separate independent section of the EBMT Registry. It focuses on the collection of information on the health outcomes of consenting individuals who have donated their bone marrow cells or other cellular material for allogeneic HCT or immune cells for cellular therapy. Donors are registered in the EBMT Registry as separate individuals and do not have any system links with the recipients (patients). This was a specific requirement in order for the EBMT Registry to fulfil the European requirements for the donor registries.

Some Donor data is registered in the Patient registry (as mentioned above) to provide a complete set of data on transplant or product used for treatment. It may even contain some data fields as in the Donor outcome registry. Since the two databases are not linked, it was not possible to avoid registering some information twice (see respective data collection forms for more details).

Every Donor registered in the EBMT Registry represents a unique individual and is assigned with:

**EBMT donor ID** - is a unique donor identifier in the EBMT Registry that is generated automatically by the system in GUID / UUID format at the moment of patient registration in the EBMT Registry. It is a long code that contains letters (English alphabetic characters: a to z) and numbers (Arabic numerals: 0 to 9) for internal system use. It is not expected that users need to use it while interacting with EBMT Registry, but in case needed, the EBMT donor ID is shown in the [Donor menu](#) Edit donor details section.

**EBMT short donor ID** - shortened version of the EBMT donor ID for the convenience of the users to be used to find donors in the system. The EBMT short donor ID consists of the last 7 digits of the EBMT donor ID.

**Donor ID** - identification is given to a donor by the collection centre or centre responsible for follow-up. This field may be empty in case only GRID is used for this donor as an identifier.

**Global registration identifier for donors (GRID)** - see <https://wmda.info/> for more details on GRID. GRID is used mostly for unrelated donors. Some donors who do not have GRID assigned will have this data field empty, and only Donor ID will be used, as explained above.

Note: The concept 'GRID for life' was withdrawn in 2017. Every issuing organisation (IO) is currently allowed to assign a new GRID to an existing but relocated donor.

Every Donor is registered with some general data as requested in the Donor Registration form and associated donor events.

## Donor event

There are two donor events: the one to report details on the donation procedure and 30 days follow-up and another one for long term follow-up. All donations of a particular individual are registered under the same donor. Information on donors is entered into the EBMT Registry by the transplant centre (or Donor Registry in case of unrelated donors).

## Users

### Users

The EBMT Registry is designed to be used by various individuals with different necessities and tasks, including, but not limited to:

- Principal Investigators,
- Data Managers,
- Other authorised staff members of a centre or hospital,
- National registries in the field of blood and/or bone marrow transplantation and IEC therapy (upon request and based on signed agreement),
- Donor centres and registries authorised staff members,
- EBMT research staff,
- Registry support team,
- Authorised Auditors or Data Monitors (perform source document verification).

A **User** is an EBMT member listed on a centre's team member list or EBMT staff who interacts with or makes use of the EBMT Registry. This includes individuals who browse content, perform searches, input or download data, or engage in any other activity within the application.

Users are registered in the EBMT Registry based on the information provided by the PI in the **EBMT Registry User Account Request form** that includes the following data: user's first name, last name (surname), email address, details of organisation/entity they represent, etc.

**User ID** - is a unique user identifier in the EBMT Registry that is generated automatically by the system at the moment of user registration in the EBMT Registry. It contains seven digits and is used when it is needed to provide a reference to a particular user within the system without sharing their personal information. User ID can be found in *the [User profile](#)*.

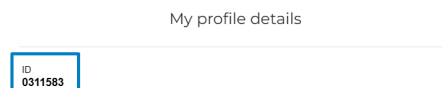


Image 5, the user ID in the EBMT Registry

**Note:** To access the new EBMT Registry database, Principal Investigators (PIs) need to submit the request on behalf of their staff members using **EBMT Registry User Account Request form**. Only requests on behalf of EBMT members listed on the centre's team member list will be accepted, all individuals must register using their professional email addresses.

Users are linked to one or multiple [Centres](#) and/or [Virtual Registries](#). This means that they represent this organisation/entity and that this organisation/entity authorises this individual to access a particular set of data and perform some tasks (see [Context](#) for more details).

When a user [Signs up](#) and [Signs in](#) to the EBMT Registry, they should indicate the following data:

### Username

This username can be used for login purposes only. It is created by the user and can contain letters, numbers and/or special characters and cannot contain any white spaces. This is not the user's first and last name, though it can contain it if the user prefers.

## Email

This is a work personal user email specified in the **EBMT Registry User Account Request form**. In case the user inputs any other personal email, they will not be able to access the requested context and will need to go through the first sign-up process once again (as a new user) with the email specified in the **EBMT Registry User Account Request form**.

## Password

This is the personal password that the user will use to enter EBMT Registry. It must satisfy all the requirements as explained under the password field, and it must:

- contain a lowercase letter;
- contain an uppercase letter;
- contain a number;
- contain at least eight characters;
- contain a special character or a space;
- not contain a leading or trailing space.

The password can be changed if needed. See [Change password](#) for instructions.

## Active/inactive users

The users in the EBMT Registry may be set as *Active* or *Inactive* by the EBMT Registry administrator or automatically.

**Inactive users** cannot get access to any data in the database. They are able to Sign in (if they have registered their username/email and created a password) but will see the message notifying them that they do not have an active account.

**Active users** can sign in to the EBMT Registry (if they registered their username/email and created a password) and then can see/access data of patients or donors linked to their centre/VR only if they have active context (if their centre or VR are set as active). If they do not have a context assigned by the administrator, or if they are linked to one inactive centre or VR, they will see an error message.

**Important:** The EBMT Registry will automatically change the user account from Active to Inactive when a user tries to log in after three or more months of not entering the system. Users should contact the EBMT Registry Helpdesk by emailing [registryhelpdesk@ebmt.org](mailto:registryhelpdesk@ebmt.org) to reactivate their user.

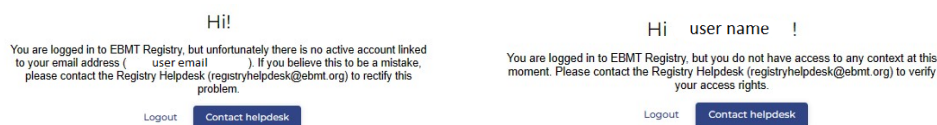


Image 6, the warning message for inactive users (L) and the message for active users with no linked context (R)

## User role

The User role refers to the set of permissions granted to a user in the EBMT Registry. Depending on their **role**, users will have access to a different set of functionalities necessary to perform their duties.

In other words, the user role defines what a user can and cannot do within the EBMT Registry.

There are the following roles in the EBMT Registry:

1. **Administrator:** oversees all other roles and manages the links between a user and centre/VR, between centre and VR, manages users (adds new users, activates or deactivates users). An administrator has access to all the functionalities other role types have.
2. **Data viewer:** can view and export entered data within their context.
3. **Data editor:** can view, add, edit and export data within their context; can see and answer data queries.
4. **Data monitor:** this role is designed for EBMT or external monitors and allows to view data, perform source document verification (SDV), and/or manage data queries. By managing queries, it is understood that a data monitor can open, answer or close a query on a particular data field from a patient event.

The roles are assigned by the EBMT Registry administrator within each user context (see [Context](#) for more details) based on submitted *EBMT Registry User Account Request form*. There is a separate form for Data viewers and Data editors.

The user role can be changed at any point to suit the needs of the user's work, allowing flexibility. If the user needs to change the role, the *EBMT Registry User Account Request form* has to be filled in with the new requested role, properly signed and sent to the EBMT Helpdesk. The user also needs to complete the EBMT training for the required role.

### **Data viewer**

The data viewer role allows the user to access minimal functionality in the EBMT Registry and thus users require minimum training.

It is an important role and should be used/requested for users who do not perform data entry, as this is the major functionality not available for data viewers. Instead, the data viewer focus is on accessing the patient/donor data (within the scope of patients or donors they received authorisation to access), on reviewing and analysing the data that has already been entered.

### **Data editor**

The data editor role allows users to access the functionality for data viewers and, additionally, data entry-related ones in the EBMT Registry.

It is an important role and should be used/requested for users who perform data entry (enter or edit data). As a data editor, such users have the ability to access, modify, and enter patient or donor data into the system and export data (within the scope of patients or donors they received authorisation to access). This role requires a high level of attention to detail and accuracy. This means users with a data editor role require more advanced training compared to data viewers.



## Centres and virtual registries

The users receive access to the scope of data through the organisation/entity they represent. There are the following two main types of such organisations/entities:

- EBMT member centres (including donor centres);
- Virtual registries.

### Centre

**Centres** use the EBMT Registry to enter and store their patients' and donors' data while simultaneously making it available to the EBMT. Members submitting data can access and use their own data for their own purposes; they do not require permission and do not need to notify the EBMT. Member centres users have access to their own data at all times. Thus, every user can see in the EBMT Registry only pseudonymised data of patients they have access to.

**Registration centre** is the centre that created the patient or donor record in the EBMT Registry. This centre will have access to the patient/donor record and patient events data even if later the patient continues the treatment in another centre or donor is being followed-up by another centre. Every patient/donor is linked to one or more centres. The registration centre is always marked in the patient/donor details. In case the registration centre disappears as an organisation (it is closed, merges with another centre, etc.), the new centre responsible for this patient will be identified and marked in the EBMT Registry as a patient registration centre. All such changes are reflected in the [audit trail](#) and can be done only by the EBMT Registry administrator.

In many cases a patient or donor is being followed-up by multiple centres, all these centres are called **reporting centres**. Thus, the access to the patient or donor record is granted to other centres involved in the data collection process through the specific form available at EBMT [website](#). Access to the patient/donor record is provided for an indefinite period.

**Note:** When referring to 'patients of a centre', it is understood all patients the centre has access to, even if this centre is not a registration centre for some of these patients.

**Centre Identification Code (CIC)** - is a unique 3-4 number code (Arabic numerals: 0 to 9) assigned to every centre in the EBMT Registry. This code is used in official communications between the EBMT and the respective centre. This item is essential for proper registration of the data submitted by the centre, as well as for other processes in the application.

### Virtual registry

**Virtual registry (VR)** is a term used to describe a number of organisations that require access to the EBMT Registry for their users and include:

- Centre-based VR (CBVR);
- Filter-based VR (FBVR);
- Hybrid VR (HVR).

**CIC** term is also used to define a unique 3-4 number code (Arabic numerals: 0 to 9) assigned to every Virtual registry in the EBMT Registry. This code is used in official communications between the EBMT and the respective VR. This item is essential for the proper registration of the data and the correct setting of access rights.

### Centre-based VR (CBVR)

It is a group of users that require access to certain centres' patient/donor data. Usually, it is an organisation that unites a number of centres based on certain criteria (regional registries, national registries, group of centres, etc.).

Representatives of centre-based VRs require access to data of patients that belong to their member centres only. For some countries, it is also a legal requirement for the national registries to have access to the data of the centres in their territory and supervise and control their activities.

### Filter-based VR (FBVR)

FBVR is a group of users that require access to patients' and/or donors' data based on certain filtering criteria (it does not matter what centre the patient belongs to). For example, a group of scientists that study a specific topic and need access to pseudonymised patient data in the EBMT Registry that satisfies a very particular set of criteria (patients with a particular diagnosis, that underwent particular treatment, born in a specific period, etc.).

Practical example: EBMT Study group as a Filter-based VR will have access to the patient's data from different centres based on their research target group criteria (e.g. age, diagnosis, transplantation type, etc.).

### Hybrid VR (HVR)

HVR is a combination of centre and filter-based VR when a group of users require access to a specifically filtered pool of patients and/or donors from a certain list of centres.

Practical example: EBMT recognised study group focused on the analysis of data of patients from particular territory is seen as Hybrid VRs, which will have access to a pool of patients' data that satisfy specific criteria from a certain list of centres.

### Active/inactive centre or VR

Administrators only can set the centre or VR status as **active** or **inactive**. Centre/VR can be set as inactive in some rare cases, for example, in order to protect the security of their data, as per legal requirements or if centre/VR does not exist anymore.

Note: Centres/VRs are not deactivated automatically by the system due to inactivity. Deactivation is always done by the EBMT Registry administrator.

If the centre/VR is inactive: users linked to this centre/VR cannot choose it as their context, and thus, they are not able to access the patients or donors within this context.

If the centre/VR is set as active: users linked to this centre/VR can see it in the list of their context (in the context menu), choose this centre as their context, and thus they are able to access the patients or donors within this context.

If a centre/VR as an organisation is to be closed, merged with another one, or the structure changes and splits, this should be reported to the EBMT Registry Helpdesk as soon as possible so that the EBMT Registry administrator can link the patients (registered by this centre) to the correct centres/VRs and make all necessary amendments. This will ensure a smooth and continuous data access and data entry process.

## Context

**Context** - is a section of the database (data of a specific list of patients/donors linked to a centre or VR) that the user can access to perform their duties in the EBMT Registry.

The name of the context is the CIC and the name of a centre or VR that authorised the user to access their patients' data. Context is always linked to the user role.

Every patient in the system is linked to one or more centres (registration centre, reporting centre, etc.). Patients may be also linked to some VRs. Context is the scope of patients a centre, or VR has access to and their data. Users cannot be linked to any patient directly. They can only use the Centre-patient or VR-patient link.

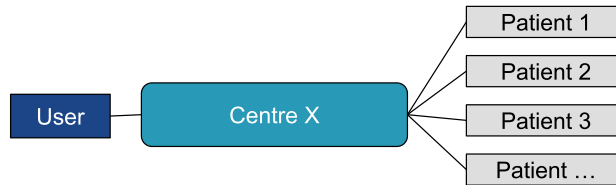


Image #, schematic view of patient linking to a center

If a user does not have access to any context or their context Centre/VR is **inactive**, they are still able to sign in, but they will see the message notifying them about this at the homepage of the application. All users should submit a properly filled and signed *EBMT Registry User Account Request form* and pass training certification to have their user activated and context assigned. If a user has already fulfilled all the steps but sees an error stating (s)he does not have access to any Context, the user should contact the EBMT Registry Helpdesk.

There are users that, due to their work particularities, have **multiple roles** and need different permissions and functionality within the EBMT Registry (e.g. they are doing patient data entry in one centre, work in a national registry and at the same time are doing a research study in the EBMT working party). In this case, the user uses the system in different contexts. For each context, the user might have the same or different role and thus, a different set of rights and permissions (see the diagram below as an example).

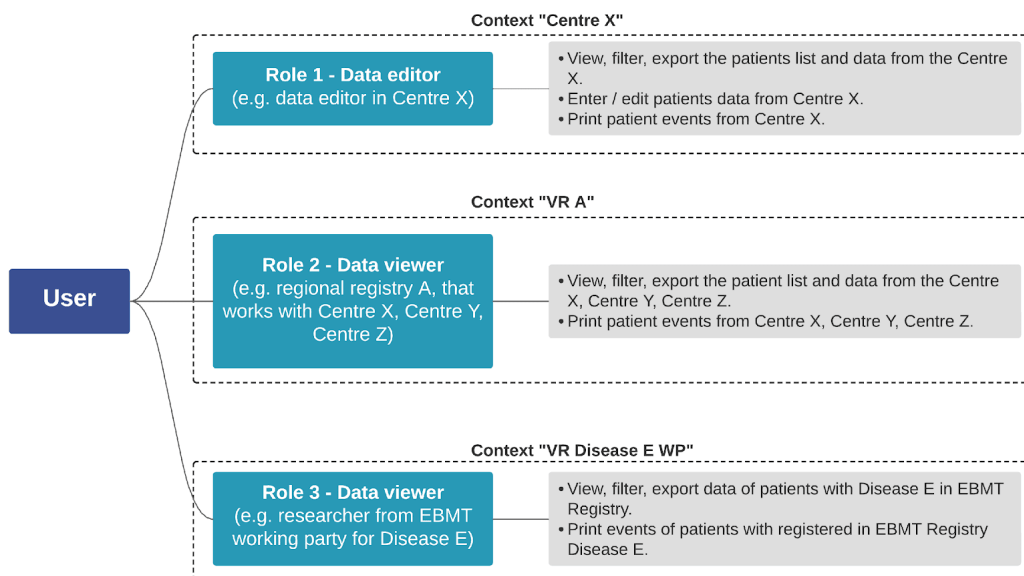


Image 8, description of a user that has multiple roles in multiple contexts

Important: in case a user has access to multiple contexts, these contexts exist independently and the user is assigned a role per each context, the rights and permissions of the user might be different in each context and are not combined.

Every user can have only one user account, which means this user is registered with one email and username and uses one password to enter the EBMT Registry. In case of multiple roles, a user logs into the system and the last used context is loaded. The user can change the context (s)he wants to work.

Only users with access to multiple contexts can switch between the contexts and can choose in which context to work without the need to log out. This can be done through the [Context menu](#).

## Interface and screen layout

The EBMT Registry layout is designed to provide a seamless user experience. The screen is divided into the following sections:

1. The EBMT Registry logo is always shown on the left upper side of the screen.
2. The header displaying the name of the section the user is currently viewing (displayed on the main screen)
3. Context menu showing the current context name and the role of the user in this context.
4. Navigation menu for accessing different sections of the application quickly and easily.
5. The main screen is where the content of the opened section is displayed.
6. EBMT Registry version.

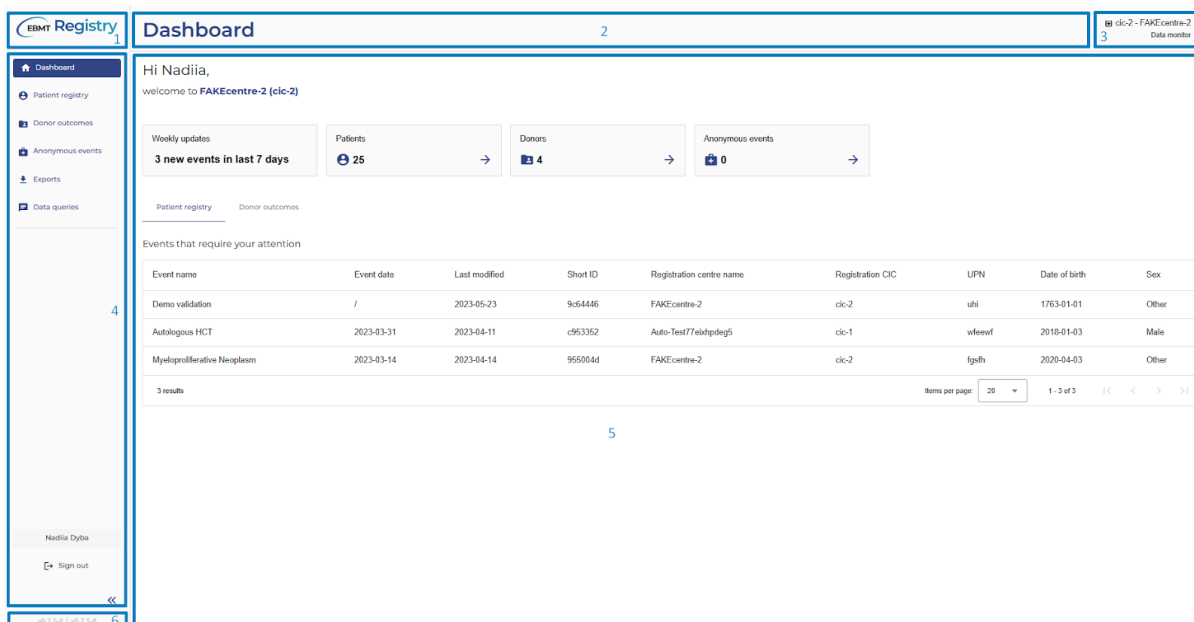


Image 9, landing page of the EBMT Registry after logging in

For sections and main screens where the overviews and long list of items is shown (like Patient registry overview, Donor outcomes overview, etc.) there is also used [Pagination](#) at the bottom of the main screen.

### Context menu

Context menu is always shown in the upper right corner of the screen regardless of what part of the EBMT Registry the user is currently in. By default, it shows the name of the Context, the user currently in and the user's role in this Context (see Image 10).

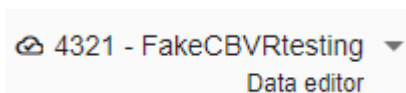


Image 10 Context menu

Users with access to multiple contexts can click on any part of the menu, and a dropdown list with all available contexts for the user will open. This list will contain only active centres or VRs and show the CIC and the name of the Centre/VR. The User role is not visible in the dropdown list.

For users with access to one context, the context menu will always show the name of the context they have access to. They cannot see the dropdown list.

## Navigation menu

Navigation menu is always displayed in the application on the left side of the screen. It includes the following navigation buttons:











Name (in full view)	Icon	Description
<b>Dashboard</b>		A button to go to the dashboard, which is the homepage of the EBMT Registry (see <a href="#">Dashboard</a> ).
<b>Patient registry</b>		A button to open the patient's overview list in the user's current context (see Patient registry).
<b>Donor outcomes</b>		A button to open the donors overview list in the user's current context (see Donor outcomes).
<b>Exports</b>		A button to open the exports overview list from all the contexts the user has access to.
<b>Anonymous events</b>		A button to open a registry of treatments for non-consenting patients.
<b>Wiki</b>		A button to open <a href="#">Wiki</a> portal.
<b>User profile</b>		A button with the user name or initials to open <i>My profile details</i> .
<b>Sign out</b>		A button to sign out (log out) from the EBMT Registry.
		A button to switch from Navigation menu full view to compact view.
		A button to switch from Navigation menu compact view to full view.

Table 1, icons used in the EBMT Registry and their descriptions

When the section is opened in the main window, the button is highlighted, e.g.  turns into



The navigation menu can be shown in **full** or **compact view**, the users can switch between them at their convenience by pressing the double arrow button. The compact view was designed to display more information on a user's main screen while working with the database.

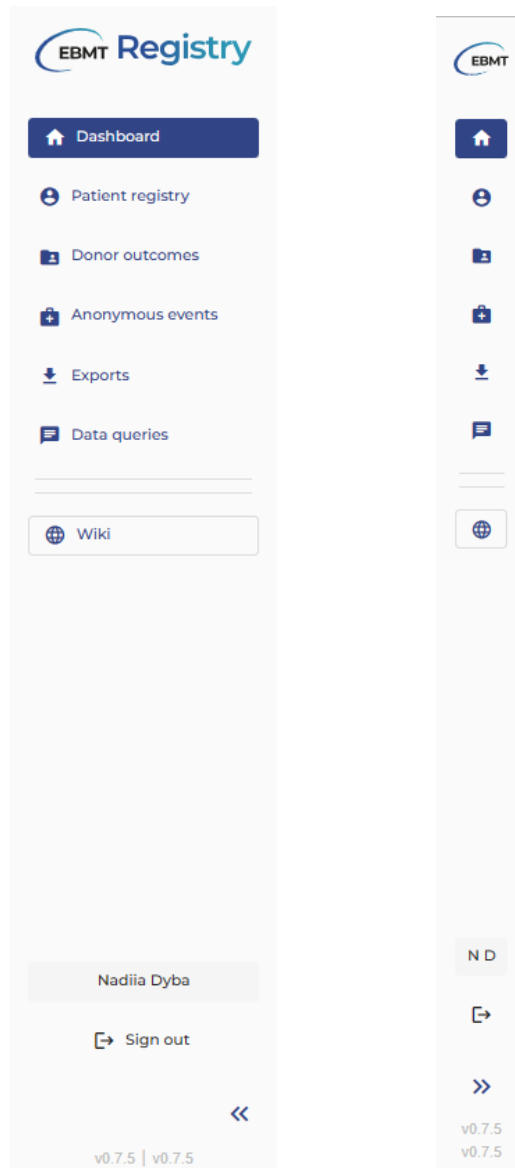


Image 11, Navigation menu in full and compact view

## Dashboard

The dashboard is the home page of the EBMT Registry application. It always shows a greeting message with the user name and the context the user is currently in.

Whenever the user changes their context, they are always redirected to the dashboard with the greeting message containing the chosen context.

In the current version of the EBMT Registry, the dashboard will contain some general information about the patients/donors recently registered in the user context as well as useful links to data requiring the user's attention, e.g. patient records with errors or warnings and some other.

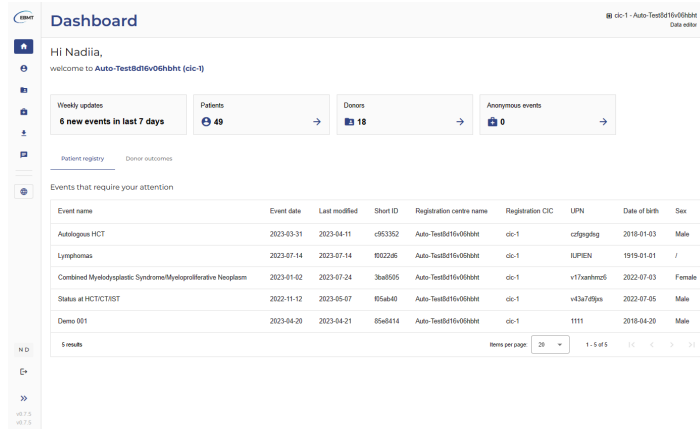


Image 12, the dashboard that is visible after logging in

Additional information and functionality will be added to the dashboard in the next versions of the application.



## Patient registry

Patient registry is part of the EBMT Registry that contains information on [patients](#) registered in the EBMT Registry and their [events](#).

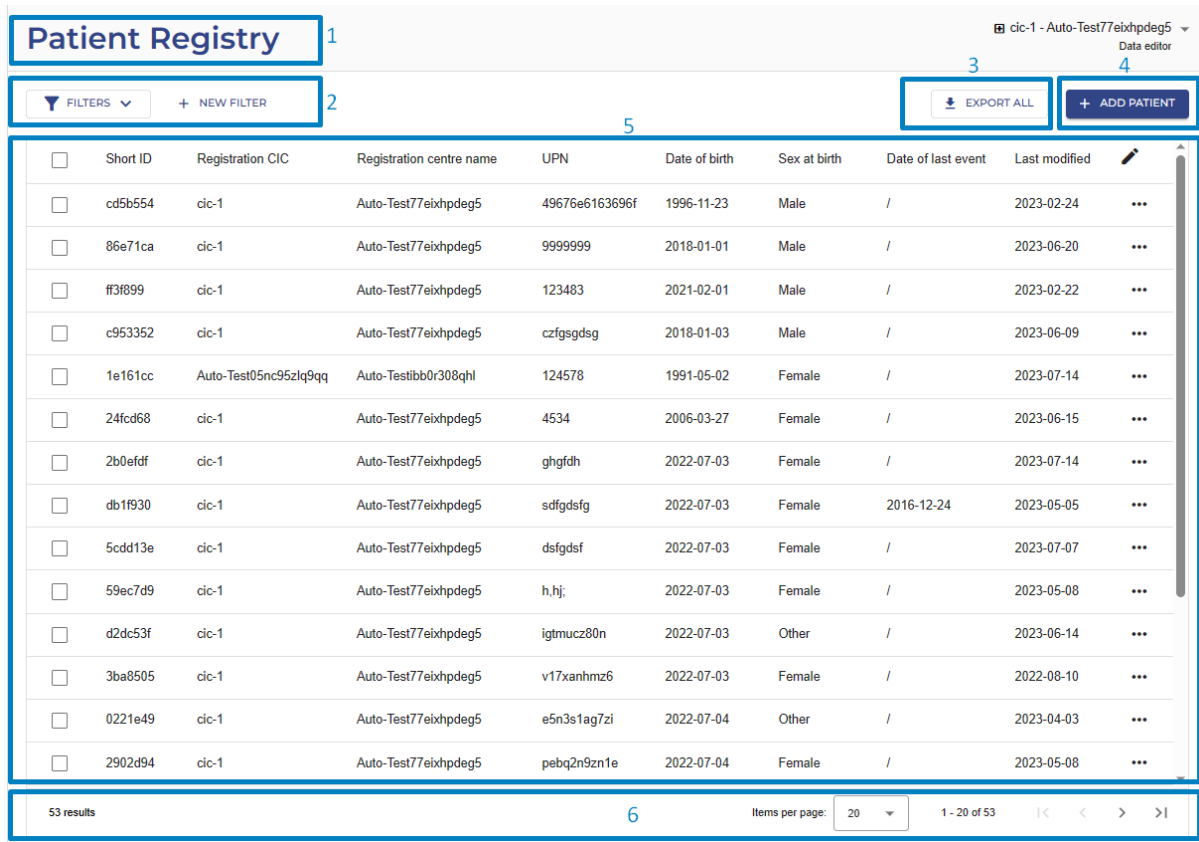


Image 13, patient registry overview

### Patient registry overview page

Patient registry overview page shows:

1. Patient Registry title. Users without editing rights (e.g. with data viewer role) will see **Read only** sign next to it, reinforcing the functionality available to them.

Patient Registry Read only

Image 14, Patient Registry title displayed for Data Viewers

2. Buttons to set up/apply filtering of the patient list (see [Filters](#)).
3. *Export all* button to export the full context (not available yet).
4. *Add patient* button to add or create a new Patient in the EBMT Registry (see [Add Patient](#)).

This button is not visible to Data viewers.

5. The list of registered patients (in the user context) with their data summary. The information in the Patient registry overview page is presented in the table, where each row corresponds to a separate patient, and columns provide the following details:

Column name	Column can be used for sorting	Description
Short ID	Yes	EBMT patient short ID.

Column name	Column can be used for sorting	Description
Registration centre CIC	Yes	The CIC of the centre that registered the patient in the EBMT Registry.
Registration centre name	Yes	The name of the centre that registered the patient in the EBMT Registry.
UPN	Yes	<ul style="list-style-type: none"> <li>• If the context is a VR - the UPN for the registration centre is shown.</li> <li>• If the context is a centre - the UPN for the context centre is shown.</li> </ul>
Date of birth	Yes	Patient date of birth as per Patient registration data.
Sex at birth	Yes	Patient sex at birth as per Patient registration data.
Date of last event	No	Date of the last registered event for this patient (the event with the most recent date). The event that is shown last (to the right) in the Patient timeline.
Last modified	No	Date the latest changes were done to any of the patient data/events.

Table 2, items in the Patient Registry overview

There is also a checkbox at the beginning of each table row to select the patient that corresponds to this row, if it is needed (see Selection).

6. [Pagination](#) section.

[Tentative patients](#) are marked in the patient overview list, and the line that corresponds to a tentative patient is greyed out (Image 15) and visible to data editors and administrators.

<input type="checkbox"/>	Short ID	Registration CIC	Registration centre name	UPN	Date of birth ↑	Sex	Date of last event	Last modified
<input type="checkbox"/>	8b52e38	cic-1	Auto-Teste2xefa3qgrw	/	2022	Male	/	2022-11-18
<input type="checkbox"/>	fad344f	cic-1	Auto-Teste2xefa3qgrw	/	2022	Male	2023-03-15	2023-03-15
<input type="checkbox"/>	5b1a3ec	cic-1	Auto-Teste2xefa3qgrw	/	2022	Female	/	2022-10-27
<input type="checkbox"/>	ed7bf98	SHD-TEST	SHD-TEST	/	2022	Male	2023-03-31	2023-02-22
<input type="checkbox"/>	2a8709d	cic-4	FAKEcentre-4	/	2022	Female	/	2022-08-31
<input type="checkbox"/>	0e24739	cic-1	Auto-Teste2xefa3qgrw	/	2022	Male	/	2022-11-18
<input type="checkbox"/>	911085a	/	/	/	2022-01-01	Other	2023-03-09	2023-03-10
<input type="checkbox"/>	9427d28	cic-4	FAKEcentre-4	/	2022-01-01	Female	/	2023-03-17

Image 15, Patient registry overview: registered patients versus tentative patients

The details on patient specific page layout and content are explained in the [Patient page](#) section.

## Donor outcome registry

Donor outcome registry is part of the EBMT Registry that contains information on [donors](#) registered in the EBMT Registry and associated with these donors [events](#).

Short ID	Registration CIC	Registration centre name	Donor number	GRID	Date of birth	Sex at birth	Date of last event	Last modified
ae19c55	cic-1	Auto-Test77eikhpdeg5	fgdfg	/	1980-05-07	Female	/	2023-07-19
c2ef340	cic-1	Auto-Test77eikhpdeg5	shgdth	/	1980-06-07	Female	/	2023-06-29
ef72990	cic-1	Auto-Test77eikhpdeg5	gyufgfgt	/	1980-07-01	Female	/	2023-07-14
524aa8f	cic-1	Auto-Test77eikhpdeg5	{{randomWord}}	/	1980-07-01	Female	/	2023-07-05
d74ef9b	cic-1	Auto-Test77eikhpdeg5	{{randomWord}}	{{randomWord}}	1980-07-01	Female	/	2023-06-20
91e0587	cic-1	Auto-Test77eikhpdeg5	up	/	1980-07-01	Female	/	2023-04-20
9c7a3fa	cic-1	Auto-Test77eikhpdeg5	Bedfordshire	/	1980-07-01	Female	/	2023-06-29
d336df0	cic-1	Auto-Test77eikhpdeg5	payment	/	1980-07-01	Female	/	2023-06-20
4ed9282	cic-1	Auto-Test77eikhpdeg5	Generic	/	1980-07-01	Female	/	2023-05-30
e4ea955	cic-1	Auto-Test77eikhpdeg5	heuristic	/	1980-07-01	Female	/	2023-07-10
1ef08b3	cic-1	Auto-Test77eikhpdeg5	models	/	1980-07-01	Female	/	2023-06-30
1c5e364	cic-1	Auto-Test77eikhpdeg5	black	/	1980-07-01	Female	/	2023-07-06
1f64c46	cic-1	Auto-Test77eikhpdeg5	violet	/	1980-07-01	Female	/	2023-07-13
377b80d	cic-1	Auto-Test77eikhpdeg5	test	/	2022	Male	/	2023-04-28
7161625	cic-1	Auto-Test77eikhpdeg5	e	test	2022	Male	/	2023-07-03
71822c7	cic-1	Auto-Test77eikhpdeg5	fgdfg1	/	1980-05-07	Female	/	2023-05-08

Image 16, Donor Outcome Registry overview

### Donor outcome registry overview page

Donor outcome registry overview page shows:

1. Donor Outcome Registry title. Users without editing rights (e.g. with data viewer role) will see the **Read only** sign next to it, reinforcing the functionality available to them.

Donor Outcome Registry Read only

Image 17, Donor Outcome Registry title displayed for Data Viewers

2. Buttons to set up/apply filtering of the donor list (see [Filters](#)).
3. **Add donor** button to add or create a new [Donor](#) in the EBMT Registry (see [Add Donor](#)). This button is not visible for Data viewers.
4. The list of registered donors (in the user context) with their data summary.
5. [Pagination](#) section.

The information in the Donor outcome registry overview page is presented in table 3, where each row corresponds to a separate donor, and columns provide the following details:

Column name	Column can be used for sorting	Description
Short ID	Yes	EBMT donor short ID
Registration centre CIC	Yes	The CIC of the centre that registered the donor in the EBMT Registry.

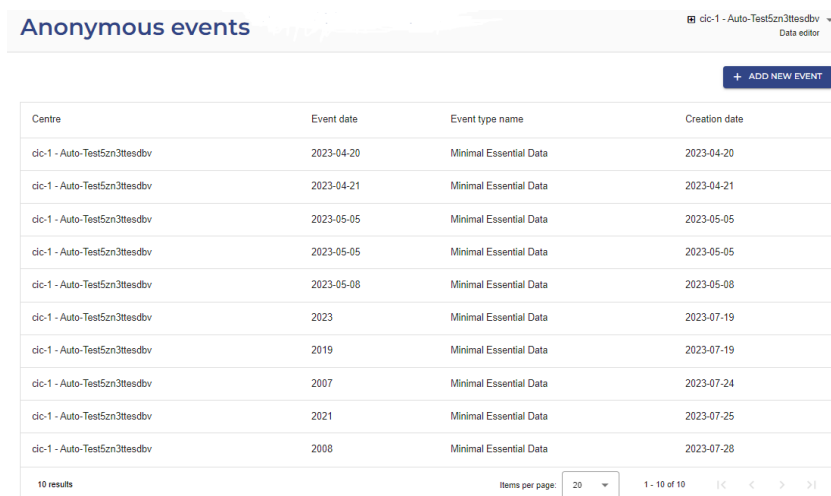
Column name	Column can be used for sorting	Description
Registration centre name	Yes	The name of the centre that registered the donor in the EBMT Registry.
Donor ID	Yes	<a href="#">Donor ID</a> given to a donor by the collection centre or centre responsible for follow-up.
GRID	Yes	<a href="#">GRID</a>
Date of birth	Yes	Donor date of birth as per Donor registration data.
Sex at birth	Yes	Donor sex at birth as per Donor registration data.
Date of last event	No	Date of the last registered event for this donor (the event with the most recent date). The event that is shown last (to the right) in the Donor timeline.
Last modified	No	Date the latest changes were done to any of the donor data/events.

Table 3, columns in the Donor outcome registry overview

## Anonymous events for non-consenting patients

If the patient did not give their consent to share their data with the EBMT, it means that only minimal essential data on the performed treatment can be entered into the EBMT Registry according to instructions available at the EBMT website: <https://www.ebmt.org/registry/data-collection>.

**Anonymous events** - is the term used to define the scope of data concerning the centre's activities related to non-consenting patients.



Centre	Event date	Event type name	Creation date
cic-1 - Auto-Test5zn3ttesdbv	2023-04-20	Minimal Essential Data	2023-04-20
cic-1 - Auto-Test5zn3ttesdbv	2023-04-21	Minimal Essential Data	2023-04-21
cic-1 - Auto-Test5zn3ttesdbv	2023-05-05	Minimal Essential Data	2023-05-05
cic-1 - Auto-Test5zn3ttesdbv	2023-05-05	Minimal Essential Data	2023-05-05
cic-1 - Auto-Test5zn3ttesdbv	2023-05-08	Minimal Essential Data	2023-05-08
cic-1 - Auto-Test5zn3ttesdbv	2023	Minimal Essential Data	2023-07-19
cic-1 - Auto-Test5zn3ttesdbv	2019	Minimal Essential Data	2023-07-19
cic-1 - Auto-Test5zn3ttesdbv	2007	Minimal Essential Data	2023-07-24
cic-1 - Auto-Test5zn3ttesdbv	2021	Minimal Essential Data	2023-07-25
cic-1 - Auto-Test5zn3ttesdbv	2008	Minimal Essential Data	2023-07-28

Image 18, view of the anonymous events

**Important:** In the current version of the application, the anonymous events are visible only to users in a centre context or Centre-based VR context.

### Anonymous events overview page

Anonymous events overview page can be open through the [Navigation menu](#), and it contains:

1. The title: Anonymous events.
2. The list of registered anonymous events (in the user [context](#)) with their data summary.
3. Add a *new event* button to add or create a new anonymous event in the EBMT Registry (see [Add anonymous event](#)).
4. [Pagination](#) section.

The information in the anonymous events overview page is presented in table 4, with each row corresponding to a separate anonymous event and columns providing the following details:

Column name	Description
Year of event	The year of treatment for a non-consenting patient.
Event type name	The type of treatment for a non-consenting patient.
Creation date	The date the anonymous event was created in the EBMT Registry to report minimal essential data for a non-consenting patient.

Table 4, columns in the Anonymous Events

**Anonymous events** are records created in the EBMT Registry to report the centre’s activities concerning non-consenting patients, and they include the following information:

- diagnosis: date, classification, subclassification;
- treatment: year, type, chronological order (sequence) of this type of treatment for this patient;
- cell source: autogenic or allogenic.

Each anonymous event has a unique identifier (7 digits) automatically created by the EBMT Registry.

The **anonymous event page** represents the following information:

1. Anonymous event unique identifier;
2. Anonymous event summary section. It also contains buttons *Save changes* to save changes (if changes were made to the saved form) and *Print* button to print the current anonymous event form.
3. Anonymous event data fields.

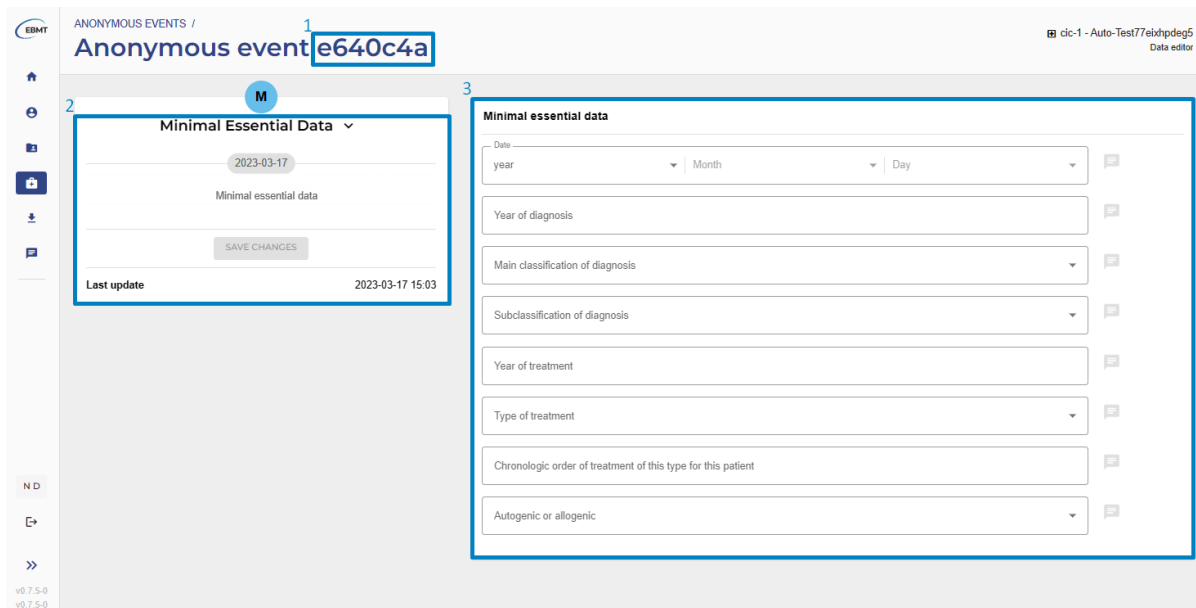


Image 19, Anonymous events data entry fields

Note: CBVR can view the anonymous events of their member centres.

**Important:** If a patient was registered in the EBMT Registry but withdrew their consent and requested their data to be removed from the EBMT Registry, the data is removed completely and is not automatically transferred into Anonymous events. From this point, the patient is considered a non-consenting patient. A centre should report the minimum essential data for this patient via an anonymous event.

## Exports

**Data export** - is a process of extracting (copying) data from the EBMT Registry [database](#) and saving it in one of the requested formats.

**Export** - is the file created by the system that contains patient data from the EBMT Registry analytical database (in [OMOP](#) CDM format): patient registration and all patient events data.

Once EBMT Registry generates the export file, it is stored in the server for 7 days and is available for download only to the user who requested its creation. After 7 days the file expires and cannot be downloaded. If a new export with the same information is required after the expiration date, the request can be created again through the Patient Registry.

**Note:** no exports can be created between 02:00 and 07:00 AM CET. This is when the synchronisation between the application and analytical database happens.

### Export security

Important: Export files contain sensitive patient and/or donor data, and thus must be protected from unauthorised access and/or use by taking appropriate security measures.

1. The download process and storage of data export files has to ensure integrity and confidentiality of the data at all times.
2. Backups have to ensure the integrity and confidentiality of data export files at all times.
3. Data export files are to be deleted according to the relevant regulations of the JCA.

It is **recommended** that, among other security measures, Users will ensure that:

1. Data export files are downloaded, located and stored in an encrypted local disk on their devices.
2. The dedicated directory will not back up automatically to any Cloud storage facility or external drive.
3. All data export files are deleted promptly, once Users finish working with them.

All users of the EBMT Registry must comply with the EBMT Registry Conditions of Use, Data Protections laws in existence in each individual country, and the General Data Protection Regulations (GDPR 2016/679). Please visit the EBMT website for more information on Data protection and privacy <https://www.ebmt.org/registry/ebmt-data-protection-privacy> and the EBMT Registry Conditions of Use.

Every time users download export file, they have to confirm by clicking 'I understand' button that they are aware of and will comply with these security requirements

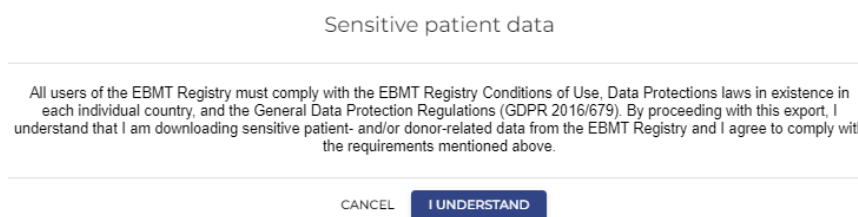


Image 20, download export file confirmation notification (warning)

### Export scope

The users can export the following scope of data within their context:

1. [Export data of all patients](#) in their context;
2. [Export data of filtered list of patients](#) in their context;
3. [Export data of manually selected list of patients](#) in their context.

Note: In the current version of the EBMT Registry, users can manually or bulk select the patients whose data (whole dataset of a patient) they want to include into the export with the limitation of 250.000 patients per export request. In case it is required to export data of more than 250.000 patients it is recommended to request it breaking into files of less than 250.000 patients or contact and request it through the Helpdesk.

**Export full context** - By clicking *Export All* as seen in the image below, the user will generate a file containing all data of all patients that are available in the current user context.

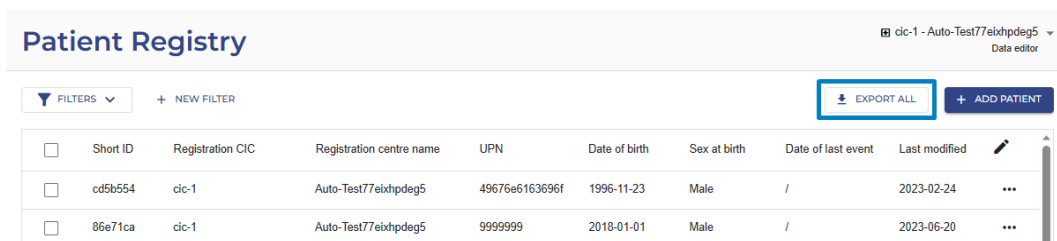


Image 21, button *Export All*

**Export filtered results** - By clicking *Export Results(number of results)* as seen in the image below, the user will generate a file containing all the data of the patients that fit the selected filtering criteria, as defined by the user through the filtering functionality.

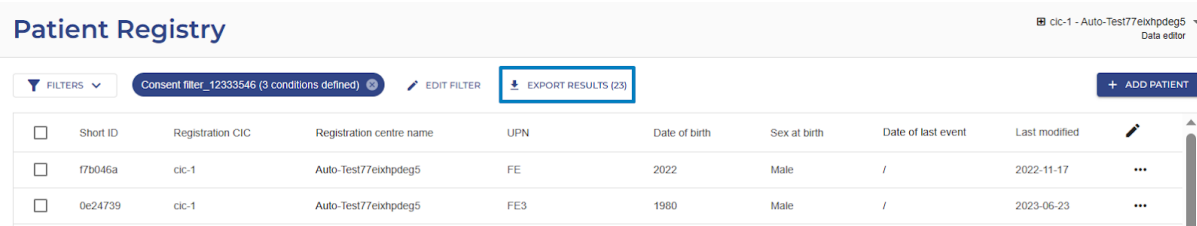


Image 22, button *Export Results (number of results)*

**Export selected list** - The user can request the EBMT Registry to generate a file that contains all the data of a selected list of patients:

- A. The selection can be made in the unfiltered [Patient overview page](#). By clicking *Data Export* as seen in the image below, the user will generate a file containing all data of patients marked through the select box. The number of selected patients (rows) is displayed in the left upper corner of the unfiltered patients list.

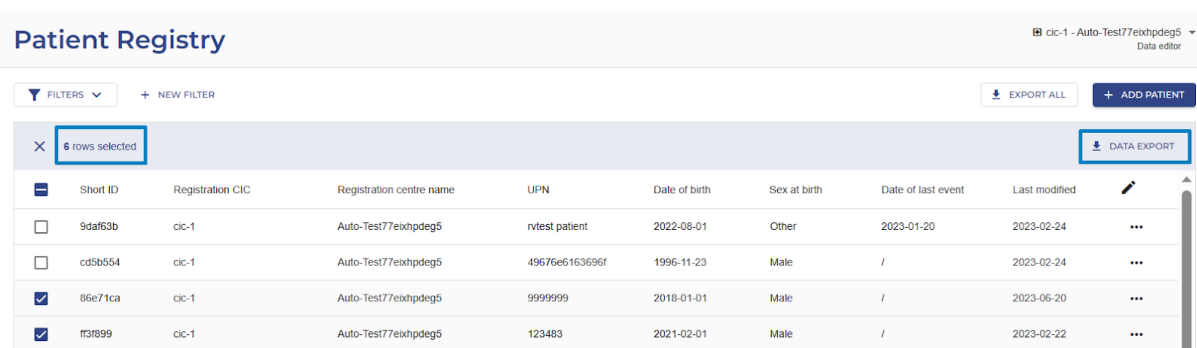


Image 23, button *Data Export* and summary of selected rows in unfiltered list of patients



B. The selection can be made in the Patient [overview page](#) with applied [filters](#), when only some of the filtered results should be exported by clicking *Data Export* as seen in the image below, the user will generate a file containing all data of patients marked through select box. The number of selected patients is displayed in the left upper corner of the filtered patients list.

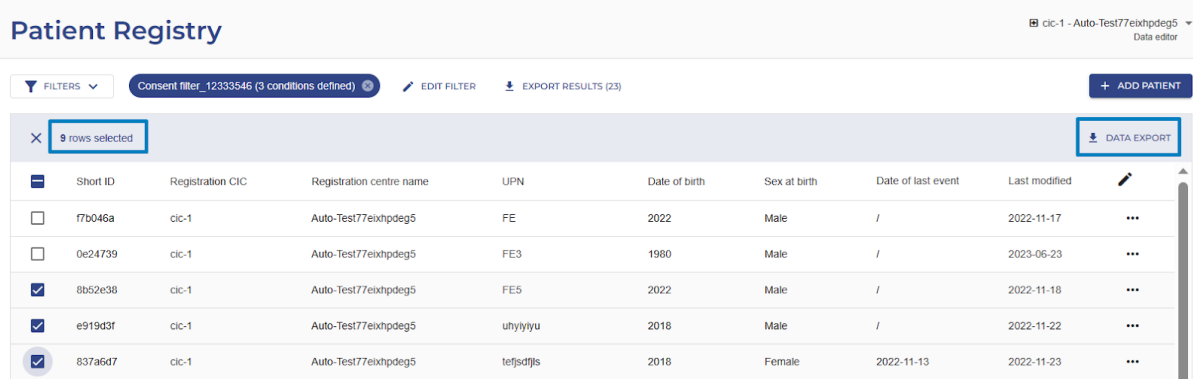


Image 24, button *Data Export* and summary of selected rows in the filtered list of patients

### Export file name and format

Data exports from EBMT Registry can be obtained in the following formats:

- Excel
- SPSS
- Stata
- CSV

At the Export request stage, the user creates the name of the file (the system will suggest a file name, but it can be edited based on the user preferences) and specifies the file type (see image below).

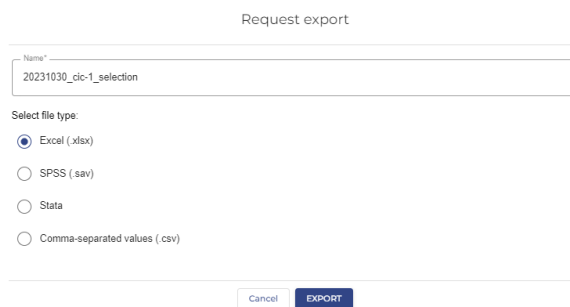


Image 25, Export file name and format

### Export file status

Data export requests may have the following status:

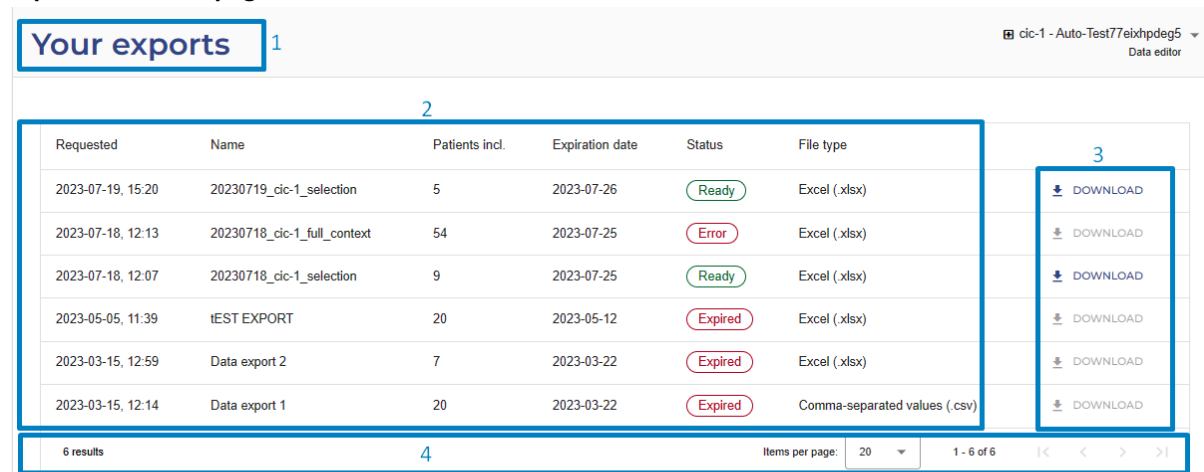
Export status	Description
Requested	The user requested data export, the export file creation has not started and is awaiting the system to pick up this request. The export is not ready to be downloaded yet.
Ready	The data export request was successfully processed. The export file is created and ready to be downloaded.
Expired	The export file is expired and is not available for download any more.

Export status	Description
Error	The data export request failed. It was not possible to create the export file.

Table 5, Export file statuses with descriptions

Note: data export requests may fail and show Error status due to various reasons. In case of error, It is recommended to repeat the attempt. If a user keeps experiencing this problem, they should contact the Registry helpdesk providing all the details of the case, including the details on the scope of data they tried to export.

### Exports overview page



Requested	Name	Patients incl.	Expiration date	Status	File type
2023-07-19, 15:20	20230719_cic-1_selection	5	2023-07-26	Ready	Excel (.xlsx)
2023-07-18, 12:13	20230718_cic-1_full_context	54	2023-07-25	Error	Excel (.xlsx)
2023-07-18, 12:07	20230718_cic-1_selection	9	2023-07-25	Ready	Excel (.xlsx)
2023-05-05, 11:39	tEST EXPORT	20	2023-05-12	Expired	Excel (.xlsx)
2023-03-15, 12:59	Data export 2	7	2023-03-22	Expired	Excel (.xlsx)
2023-03-15, 12:14	Data export 1	20	2023-03-22	Expired	Comma-separated values (.csv)

Image 25, Export overview page

Exports overview page shows:

1. The title of the page: Your exports. The export file list is for the current user and it is not accessible to other users of EBMT Registry.
2. The list of the data export files requested by the user in the EBMT Registry. If a user has access to multiple contexts, this list will contain all requests for all user contexts. The information is presented in the table, where each row corresponds to a separate export file, and columns provide the following details:

Column name	Description
Requested	Date and time the user requested to create an export file.
Name	Name of the file the user indicated while initiating this data export.
Patients incl.	The number of patients, whose data the user requested to include into this data export.
Expiration date	The date this data export expires. This means that the file will be available for download up till the specified date.
Status	Status of the data export file.
File type	The format of the data export file requested by the user for this data export.

Table 6, columns in the Exports overview

3. Download button(s): the download button can be shown in two modes as described in the table below:

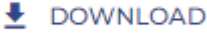

Download button mode	Description
	<p><i>Download</i> button is highlighted to indicate that the download of the data export file is available to the user.</p>
	<p><i>Download</i> button is greyed out to indicate that the download of the data export file is not possible.</p>

Table 7, Download button modes with description

4. [Pagination](#) section.

**Export content**

After downloading the requested export, a .zip file becomes visible in the 'Downloads' folder of the user's computer. After unzipping the file and opening the folder, the user will find 1 file:

- Treatment\_overview

The detailed explanation on Treatment\_overview is provided in the [Appendix 1](#).

## User profile

Users can access and view their profile information by clicking the button with their name and surname (when the navigation menu is in full mode) or initials (when the navigation menu is in compact view) from the navigation menu to call the *My profile details* modal window.

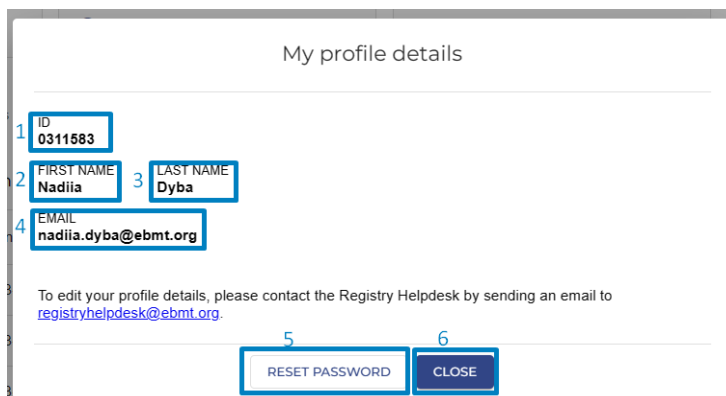


Image 26: *My profile details* modal window

The *My profile details* modal window appears on top of any previously opened section of the EBMT Registry. It shows the following information:

1. [User's ID](#) - ID number automatically assigned to the user in the EBMT Registry.
2. User's first name.
3. User's last name (surname).
4. User's email address, used for registration in the EBMT Registry.
5. Button *Reset password* - used to request a password reset.
6. Button *Close* - used to close *My profile details* modal window.

A user cannot change any information displayed in the *My profile details* modal window. If changes are required to the user's first or last name, the user can contact EBMT Registry helpdesk by email.

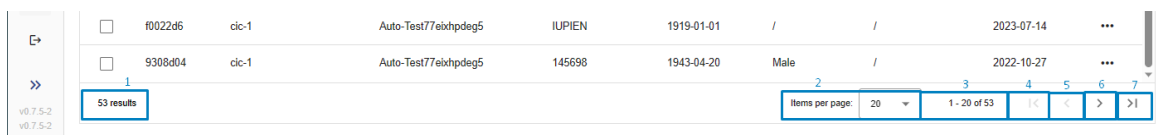
Note: User email addresses cannot be changed. If a previous email becomes unavailable, the user should contact EBMT Registry helpdesk to deactivate the previous user account and submit a properly signed and filled *EBMT Registry User Account Request form* with the updated email so that the new user account can be set up.

## Pagination

Main screens that show a long list of items with big datasets (like Patient registry overview, Donor outcomes registry overview, Data queries overview, etc.) will include pagination at the bottom of the main screen to navigate through the list of available items.

The EBMT Registry uses an offset pagination method to manage large datasets and display them on a webpage. It is a method to split a large amount of data into smaller, more manageable chunks. With offset pagination, only a portion of the data is loaded at a time, making the web page load faster and reducing the load on the system.

In the current version of the EBMT Registry the system loads up to 1,000 items (10 pages of up to 100 items) at a time. This can be changed without prior notice to adjust system performance.



	Short ID	Registration CIC	Registration centre name	UPN	Date of birth	Sex at birth	Date of last event	Last modified
<input type="checkbox"/>	f022d6	cic-1	Auto-Test77eixhpdeg5	IUPIEN	1919-01-01	/	/	2023-07-14
<input type="checkbox"/>	9308d04	cic-1	Auto-Test77eixhpdeg5	145698	1943-04-20	Male	/	2022-10-27

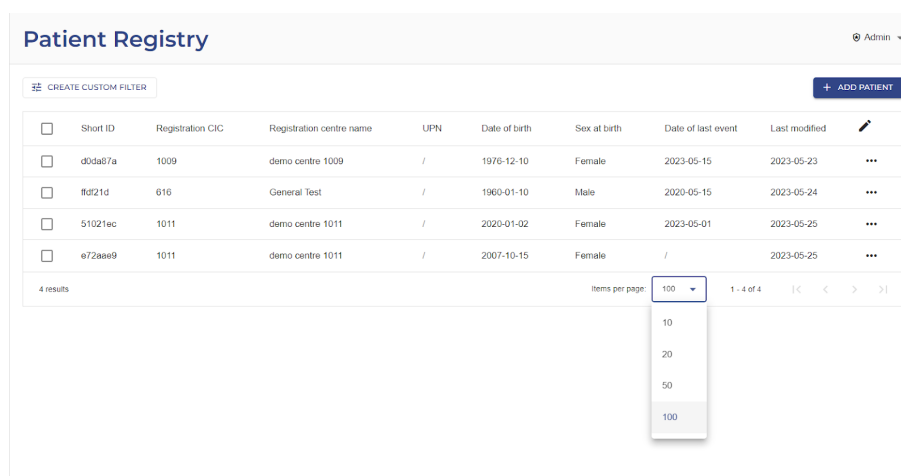
Image 21, footer showing the pagination

The pagination section includes:

1. The total number of items in the overview list (equivalent to the number of table rows).

The system will calculate this number over 1 second and display where possible. Please be aware that very big datasets may not show the total number of items to ensure it does not decrease the general system performance.

2. The number of items (table rows) shown per page. There is also a dropdown for the user to choose whether to show 5, 10, 15, 20 or 100 items per page.
3. Indication as to what rows are currently being shown on the main screen (e.g.1-100 of 1,000 represents that out of over 1,000 items in the database, items 1 to 100 are currently being shown).
4. Button to go to the first page of the list of loaded items.
5. Button to go to the previous page with the list of items.
6. Button to go to the next page with the list of items.
7. Button to go to the last page with the list of loaded items.



Short ID	Registration CIC	Registration centre name	UPN	Date of birth	Sex at birth	Date of last event	Last modified
d0da87a	1009	demo centre 1009	/	1978-12-10	Female	2023-05-15	2023-05-23
ffdf21d	616	General Test	/	1960-01-10	Male	2020-05-15	2023-05-24
51021ec	1011	demo centre 1011	/	2020-01-02	Female	2023-05-01	2023-05-25
e72aae9	1011	demo centre 1011	/	2007-10-15	Female	/	2023-05-25

Image 27, dropdown to view more patients per page

## Sorting

Main screens showing tables with datasets also offer users sorting functionality for some columns. Sorting allows the user to organise and view data more meaningfully: in ascending or descending order based on a specific column.

Ascending order:

- If sorting a column of numbers, the smallest number appears first, followed by larger numbers;
- If sorting a column of text, the values are arranged alphabetically, with the first letter of the alphabet appearing first, followed by subsequent letters;
- If sorting dates, the earliest date appears first, followed by later dates.

Descending order is the opposite of ascending order.

Sorting icon	Description
↑	Ascending order icon is not highlighted to mark that the sorting is not used for this column.
↑	Ascending order icon is highlighted to mark that the sorting is applied for this column. The items in this column are shown in ascending order.
↓	Descending order icon is highlighted to mark that the sorting is applied for this column. The items in this column are shown in descending order.

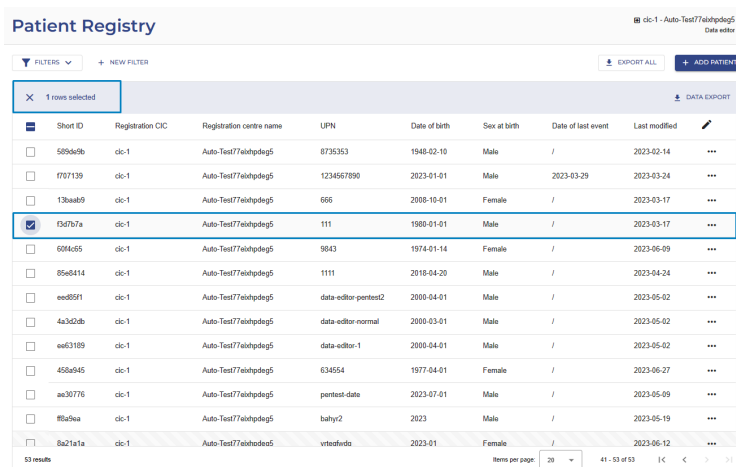
Table 9, icons for sorting columns in the EBMT Registry

It is important to note that sorting is not available for all table columns. Users can hover their mouse/cursor over the column header. If one of the sorting icons appears, this column can be used for sorting.

**Note:** sorting is done within the whole list of items in the EBMT Registry database (not only within a loaded chunk of data as per offset pagination).

## Selection and bulk selection

Main screens that show tables of data allow users to select the rows they are interested in by clicking a checkbox next to a row. Once a row is selected, the summary on the number of selected rows (items) is updated and displayed above the table. Selection can be done on various pages of the loaded data. Unselection of any selected row is done the same way by clicking a checkbox.



Short ID	Registration CIC	Registration centre name	UPN	Date of birth	Sex at birth	Date of last event	Last modified
<input type="checkbox"/> 589d6b	cic-1	Auto-Test77eibpdeg5	8735353	1948-02-10	Male	/	2023-02-14
<input type="checkbox"/> ff07139	cic-1	Auto-Test77eibpdeg5	1234567890	2023-01-01	Male	2023-03-29	2023-03-24
<input type="checkbox"/> 13baab9	cic-1	Auto-Test77eibpdeg5	666	2008-10-01	Female	/	2023-03-17
<input checked="" type="checkbox"/> f5d787a	cic-1	Auto-Test77eibpdeg5	111	1988-01-01	Male	/	2023-03-17
<input type="checkbox"/> 60f4c65	cic-1	Auto-Test77eibpdeg5	9843	1974-01-14	Female	/	2023-06-09
<input type="checkbox"/> 85e8414	cic-1	Auto-Test77eibpdeg5	1111	2018-04-20	Male	/	2023-04-24
<input type="checkbox"/> ee892f1	cic-1	Auto-Test77eibpdeg5	data-editor-pentest2	2000-04-01	Male	/	2023-05-02
<input type="checkbox"/> 4a3d2db	cic-1	Auto-Test77eibpdeg5	data-editor-normal	2009-03-01	Male	/	2023-05-02
<input type="checkbox"/> ee63189	cic-1	Auto-Test77eibpdeg5	data-editor-1	2000-04-01	Male	/	2023-05-02
<input type="checkbox"/> 458a945	cic-1	Auto-Test77eibpdeg5	634554	1977-04-01	Female	/	2023-06-27
<input type="checkbox"/> aa30776	cic-1	Auto-Test77eibpdeg5	pentest-date	2023-07-01	Male	/	2023-05-09
<input type="checkbox"/> 88a95aa	cic-1	Auto-Test77eibpdeg5	bahy0	2023	Male	/	2023-05-19
<input type="checkbox"/> 8a21a1a	cic-1	Auto-Test77eibpdeg5	vrtestfvdo	2023-01	Female	/	2023-06-12

Image 28, selection of a patient row, number of selected rows

Bulk selection is needed to perform an action on more than one row at the same time instead of performing the action row by row. The selection is always done from a table. The checkbox to the left of the table header is used to bulk select the items loaded in the main screen page. The same checkbox is used to unselect in bulk all the rows on the loaded page.

Patient Registry dic-1 - Auto-Test77einhpddeg5  
Data editor

<input type="checkbox"/>	Short ID	Registration CIC	Registration centre name	UPN	Date of birth	Sex at birth	Date of last event	Last modified	
<input type="checkbox"/>	cd5b554	dic-1	Auto-Test77einhpddeg5	49676e163696f	1996-11-23	Male	/	2023-02-24	...
<input type="checkbox"/>	86e71ca	dic-1	Auto-Test77einhpddeg5	9999999	2018-01-01	Male	/	2023-06-20	...
<input type="checkbox"/>	#3B99	dic-1	Auto-Test77einhpddeg5	123483	2021-02-01	Male	/	2023-02-22	...
<input type="checkbox"/>	c953352	dic-1	Auto-Test77einhpddeg5	crfgrgdtg	2018-01-03	Male	/	2023-06-09	...

Image 29, bulk selection

When performing a bulk selection, the user bulk selects all the rows loaded in the main screen page. Thus if there are more items on the next pages (see [Pagination](#)), they should be selected or bulk selected separately as needed.

Patient Registry dic-1 - Auto-Test77einhpddeg5  
Data editor

X 20 rows selected DATA EXPORT

<input checked="" type="checkbox"/>	Short ID	Registration CIC	Registration centre name	UPN	Date of birth	Sex at birth	Date of last event	Last modified	
<input checked="" type="checkbox"/>	cd5b554	dic-1	Auto-Test77einhpddeg5	49676e163696f	1996-11-23	Male	/	2023-02-24	...
<input checked="" type="checkbox"/>	86e71ca	dic-1	Auto-Test77einhpddeg5	9999999	2018-01-01	Male	/	2023-06-20	...
<input checked="" type="checkbox"/>	#3B99	dic-1	Auto-Test77einhpddeg5	123483	2021-02-01	Male	/	2023-02-22	...
<input checked="" type="checkbox"/>	c953352	dic-1	Auto-Test77einhpddeg5	crfgrgdtg	2018-01-03	Male	/	2023-06-09	...
<input checked="" type="checkbox"/>	1e161cc	Auto-Test05nc5cshpqq	Auto-Test88b0308qhl	124578	1991-05-02	Female	/	2023-07-14	...
<input checked="" type="checkbox"/>	24fc068	dic-1	Auto-Test77einhpddeg5	4534	2006-03-27	Female	/	2023-06-15	...
<input checked="" type="checkbox"/>	2b0efdf	dic-1	Auto-Test77einhpddeg5	ghgfdh	2022-07-03	Female	/	2023-07-14	...
<input checked="" type="checkbox"/>	db1930	dic-1	Auto-Test77einhpddeg5	sdffgdtg	2022-07-03	Female	2016-12-24	2023-05-05	...
<input checked="" type="checkbox"/>	5cd413e	dic-1	Auto-Test77einhpddeg5	dtfgdtf	2022-07-03	Female	/	2023-07-07	...
<input checked="" type="checkbox"/>	59ec7d9	dic-1	Auto-Test77einhpddeg5	h.jj	2022-07-03	Female	/	2023-05-08	...
<input checked="" type="checkbox"/>	d2dc53f	dic-1	Auto-Test77einhpddeg5	lgtmucc8ln	2022-07-03	/	/	2023-06-14	...
<input checked="" type="checkbox"/>	3ba8505	dic-1	Auto-Test77einhpddeg5	v17xanhmz6	2022-07-03	Female	/	2022-08-10	...
<input checked="" type="checkbox"/>	0221e49	dic-1	Auto-Test77einhpddeg5	e5n3e1ao7zi	2022-07-04	/	/	2023-04-03	...

53 results Items per page: 20 1 - 20 of 53

Image 30, bulk selection, number of selected rows

Deselection of all the rows on all pages can be done by clicking X icon next to the summary on the number of selected rows (items) above the table.

Patient Registry dic-1 - Auto-Test77einhpddeg5  
Data editor

X 36 rows selected DATA EXPORT

<input checked="" type="checkbox"/>	Short ID	Registration CIC	Registration centre name	UPN	Date of birth	Sex at birth	Date of last event	Last modified	
<input type="checkbox"/>	cd5b554	dic-1	Auto-Test77einhpddeg5	49676e163696f	1996-11-23	Male	/	2023-02-24	...
<input type="checkbox"/>	86e71ca	dic-1	Auto-Test77einhpddeg5	9999999	2018-01-01	Male	/	2023-06-20	...
<input type="checkbox"/>	#3B99	dic-1	Auto-Test77einhpddeg5	123483	2021-02-01	Male	/	2023-02-22	...
<input type="checkbox"/>	c953352	dic-1	Auto-Test77einhpddeg5	crfgrgdtg	2018-01-03	Male	/	2023-06-09	...
<input checked="" type="checkbox"/>	1e161cc	Auto-Test05nc5cshpqq	Auto-Test88b0308qhl	124578	1991-05-02	Female	/	2023-07-14	...
<input checked="" type="checkbox"/>	24fc068	dic-1	Auto-Test77einhpddeg5	4534	2006-03-27	Female	/	2023-06-15	...
<input type="checkbox"/>	2b0efdf	dic-1	Auto-Test77einhpddeg5	ghgfdh	2022-07-03	Female	/	2023-07-14	...
<input type="checkbox"/>	db1930	dic-1	Auto-Test77einhpddeg5	sdffgdtg	2022-07-03	Female	2016-12-24	2023-05-05	...
<input type="checkbox"/>	5cd413e	dic-1	Auto-Test77einhpddeg5	dtfgdtf	2022-07-03	Female	/	2023-07-07	...
<input checked="" type="checkbox"/>	59ec7d9	dic-1	Auto-Test77einhpddeg5	h.jj	2022-07-03	Female	/	2023-05-08	...
<input type="checkbox"/>	d2dc53f	dic-1	Auto-Test77einhpddeg5	lgtmucc8ln	2022-07-03	/	/	2023-06-14	...
<input type="checkbox"/>	3ba8505	dic-1	Auto-Test77einhpddeg5	v17xanhmz6	2022-07-03	Female	/	2022-08-10	...
<input type="checkbox"/>	0221e49	dic-1	Auto-Test77einhpddeg5	e5n3e1ao7zi	2022-07-04	/	/	2023-04-03	...

53 results Items per page: 20 1 - 20 of 53

Image 31, selection, number of selected rows

## Filters

The EBMT Registry has various filtering options that allow users to filter the large datasets within their context to find the required data, narrow down the search, or define the list of patients or donors that meet certain filter criteria.

There are two types of filters in the EBMT Registry:

- System filters (to be added in upcoming versions of the EBMT Registry);
- Personal filters.

### Personal filters

Personal filters are user-specific filters. They may be [created](#) and applied by a specific user to filter the list of items in the user context. Users can also [save](#) their filter if they wish to keep it and/or use it again in the future. Any saved personal filter can also be [edited](#) or deleted by the user if the filter is no longer relevant for the user.

Users can create their own personal filter in two ways:

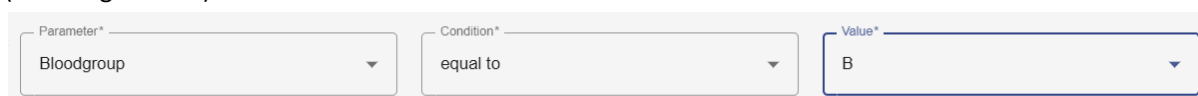
- Enter all the filtering criteria manually;
- Open a saved filter and modify it.

**Filter results** - is the list of items received after applying all criteria defined in the filter. Suppose the initial filter results do not fully meet the user's needs. In that case, the user can refine or modify the filter: adjust the criteria, remove some existing criteria or add new criteria to narrow down the displayed list further. The user can also remove the applied filter to return to an unfiltered list of items, which is the complete list of patients or donors in their context.

### Filter criteria

Filter criteria are the rules used to narrow the search results. E.g., If a user wants to filter data only to show patients born in a specific period.

To define the filter criteria, a user must specify three key components: parameter, condition and value (see image below).



The image shows a form with three dropdown menus. The first dropdown is labeled 'Parameter\*' and has 'Bloodgroup' selected. The second dropdown is labeled 'Condition\*' and has 'equal to' selected. The third dropdown is labeled 'Value\*' and has 'B' selected.

Image 32, filter criteria includes parameter, condition and value.

### Parameter

A filter parameter is the data field a user wants to search for in the database.

Filters can be applied to various data fields thus filter parameters can be related to:

- Patient/Donor (data fields related to the patient/donor registration form e.g. Blood group, Sex at birth, etc.); or
- [Patient events/Donor events](#): user also specifies the filter criteria that is related to what event type category and to what exact event (the Data Collection Form).

Since patients may have repeated events (e.g. multiple auto-HCT), it is also possible to narrow the search and specify whether it refers to the First event type, Last event type or Any event type (Image 29).



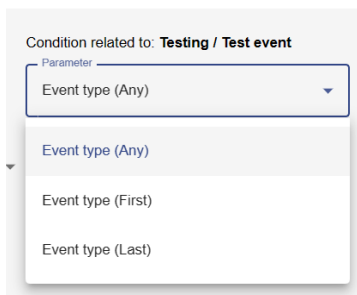


Image 33, Event type - Anythree First, Last

### Condition

A filter condition is the type of comparison a user sets up. See Table 10 below for the list of conditions used in the EBMT Registry with some examples.

Condition	Example
Equal to	Tentative (patient) equal to true.
Not equal to	Blood Group not equal to B
Greater than	Age (at treatment) is greater than 30
Greater than or equal to	Age (at treatment) is greater than or equals to 30
Less than	Age (at diagnosis) is less than 70
Less than or equal to	Age (at diagnosis) is less than or equals to 70
Is after	Treatment year is after 2000
Is before	Treatment year is before 2020

Table 10, Filter conditions and examples

### Value

Value is the reference value of the data field.

Note: in order to create a correct personal filter, a user needs to specify the filter criteria correctly: identify the data field, the event that contains this data field and the event category.

### Complex filters

Users can filter the list of patients or donors within their context based on a number of **filter criteria** to search for patients/donors, create a filtered list of patients or work with it at their own discretion. Filtering of the patient/donor list may be based on many criteria, which may be grouped into **filter groups** for user convenience. It is possible to use either statement AND or statement OR inside each group of criteria (see example below).

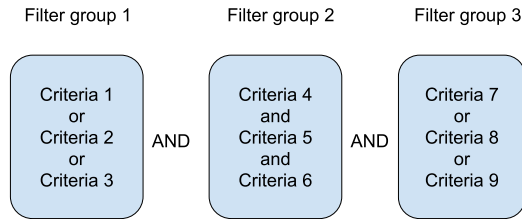


Image 34, example of filter with 'and' groups

The statement between groups of criteria is always the same and is either AND or OR. It cannot be a combination of both (see example above and below).

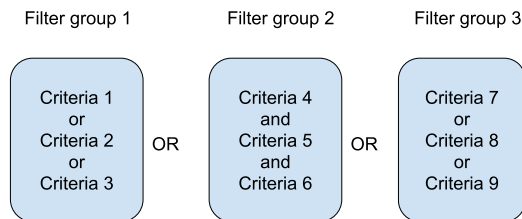


Image 35, example of filter with 'or' groups

By default, the statement AND is always shown, but the statement can be changed at any time while setting the filter both inside the group and between groups.

Create a population filter

Bloodgroup equal to B

+ Add condition

AND Condition related to: Diagnosis / Plasma Cell Disorders (PCD) Incl. Multiple Myeloma (MM)

Parameter: Event type (Any) Condition: Equals Value: Plasma Cell Disorders (PCD) Incl. ...

AND Parameter: Date of diagnosis Condition: before Value: 2016-01-01

+ Add condition

AND ADD CONDITION, RELATED TO...

+ Patient + Treatment + Diagnosis + Follow-up + Testing

AND OR

Condition related to: Patient

AND Parameter: Date of birth Condition: before Value: 2016 Month Day

Parameter: Sex at birth Condition: equal to Value: Male

Cancel Reset APPLY

Image 36, example of a complex filter in the EBMT Registry

## Patient/Donor page

All patients and donors registered in the EBMT Registry have their own page. The table below lists sections and explains the structure of each patient and donor-specific page.

	Patient page	Donor page
1	Hyperlink <b>REGISTRY</b> used to come back to the <a href="#">Patient registry overview page</a> .	Hyperlink <b>DONOR OUTCOME REGISTRY</b> used to come back to the <a href="#">Donor outcome registry overview page</a> .
2	<a href="#">EBMT patient short ID</a> is always shown in the header.	<a href="#">EBMT donor short ID</a> is always shown in the header.
3	<a href="#">Patient menu</a>	<a href="#">Donor menu</a>
4	<a href="#">Patient details summary</a>	<a href="#">Donor details summary</a>
5	<a href="#">Timeline</a>	
6	<b>Create new event</b> button - not visible for data viewers.	
7	<a href="#">Event form</a> - the most recent event from the timeline is loaded by default.	
8	<a href="#">Event form summary</a> for the loaded event from.	

Table 11, sections in the patient and/or donor pages

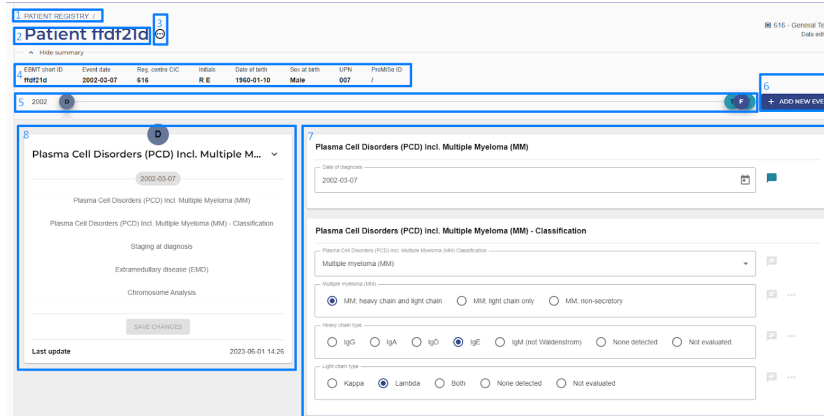


Image 37, Patient page

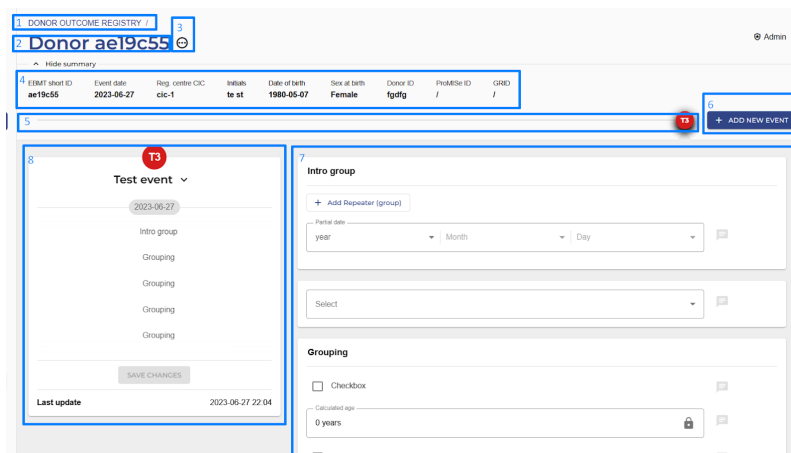


Image 38, Donor page

### Tentative patient page

[Tentative patient](#) pages are marked to call data editor and administrator users attention to the tentative status (Image 30):

- there is a word warning next to the patient menu stating *Pending verification*;
- all the upper part of the main screen except event form and event form summary is greyed out.

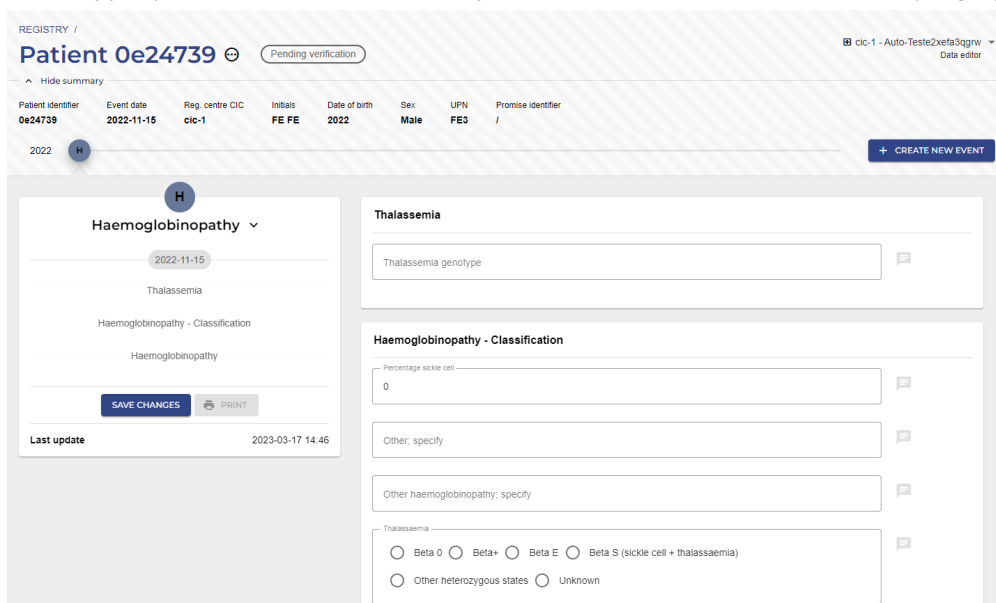


Image 39, view of a tentative patient

Remember: Only data editors and administrators can see [Tentative patient\(s\)](#) in the system. This means that Data viewers and Monitors cannot open Tentative patient pages.

### Patient/Donor menu

The **Patient/Donor menu** may be opened with the three dots button next to the Patient short ID (Image 40) or Donor short ID (Image 41). It is used to edit or update patient/donor registration information, consent, and information on studies. The functionality available for a user role is always highlighted. The functionality that is not available to a user is greyed out. Edit patient details section includes information

about EBMT patient ID, and Edit donor details section includes information about EBMT donor ID, in case it is needed to check this in the user interface.



Image 40, Patient menu



Image 41, Donor menu

Patient menu item/User role	Data viewer/Monitor	Data editor	Administrator
Edit patient details	Read only	Editable	Editable
Manage centres	Read only	Read only	Editable
Manage consent	Read only	Read only	Editable
Manage studies	Read only	Editable	Editable

Table 12, items in the patient menu and users' editing rights

Donor menu item/User role	Data viewer/Monitor	Data editor	Administrator
Edit donor details	Read only	Editable	Editable
Manage centres	Read only	Read only	Editable
Manage consent	Read only	Read only	Editable

Table 13, items in the donor menu and users' editing rights

## Patient/Donor summary

**Patient/Donor summary** is a section showing summary information about the Patient/Donor to provide users with some contextual details about the patient/donor while they are viewing events information. The content of this section may slightly change between the versions of the EBMT Registry application.

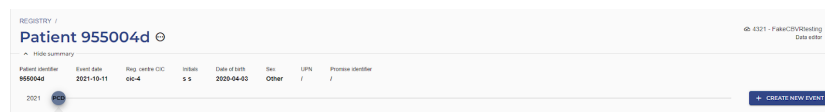


Image 42, Patient summary full view.

Patient/donor summary can be shown (in full view) as in Image 33 or hidden as in Image 34 to leave more screen space for the event form. *Hide summary* and *Show summary* are toggle buttons to switch between these two modes.

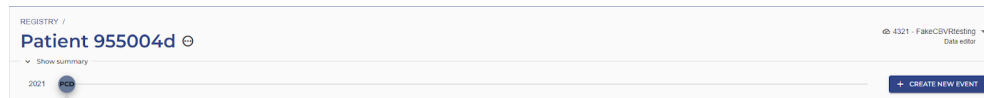



Image 43, Patient summary hidden.

## Patient/Donor timeline

**Patient and Donor timeline** represents a summary of registered events for the particular patient or donor. Events are shown as coloured circles (see Image 44) in the timeline based on the registered event date (e.g. for patients: date of diagnosis, date of follow-up, etc.) in chronological order, with the earliest events shown on the left side and all further events to the right. It allows users to see the entire registered medical history and intensity of patient/donor events over time at a glance.

Event forms with the same event date (e.g. Treatment and Disease status at HCT/CT/IST) are shown with a plus sign to visually represent that they took place on the same date (e.g. ).

Since the intensity of events may differ throughout medical history, some events are displayed very close to each other, while others might be placed further away. In order to see all the events clearly, there is a square zoom area that appears when a user hovers the mouse over the event circle in the timeline (see Image 44).

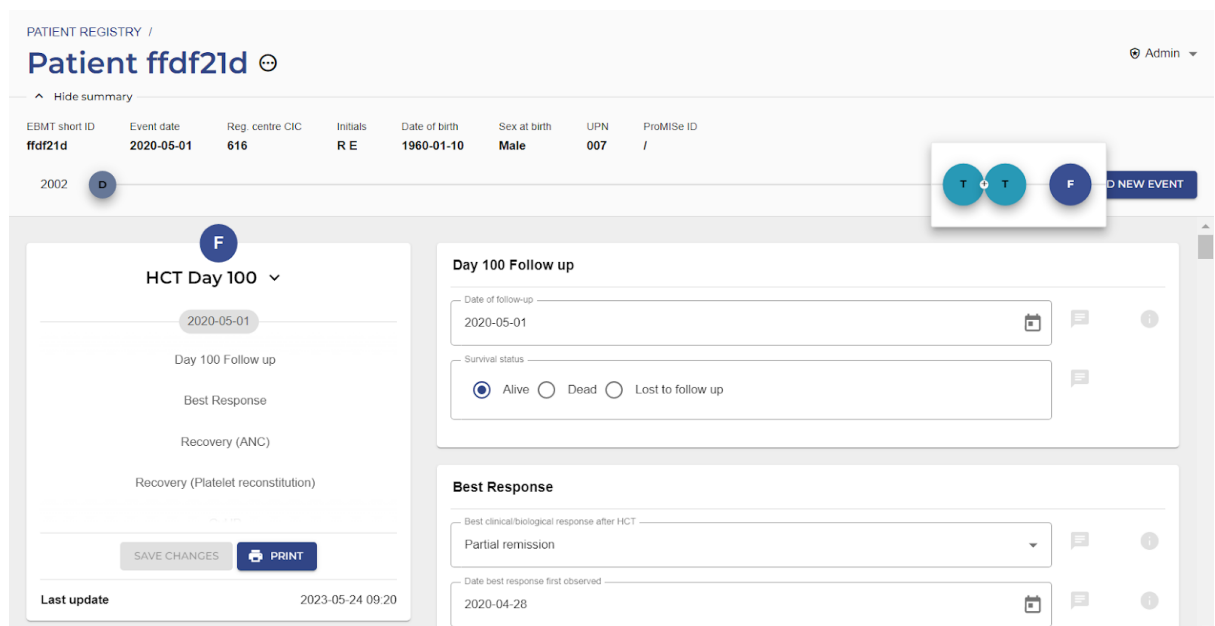


Image 44, Patient timeline

When a user hovers the mouse over the event circle in a timeline, user can see some summary information that includes:

1. Coloured circle representing an event with a letter(s) representing the category of the event (e.g. D for the diagnosis, T for treatment, etc).
2. Name of the event.
3. Date of the event.
4. The date when the event form was last updated in the EBMT Registry.
5. How much time has passed since the event took place:
  - a. It is shown in months for events less than a year ago;
  - b. It is shown in full years for events over a year ago.

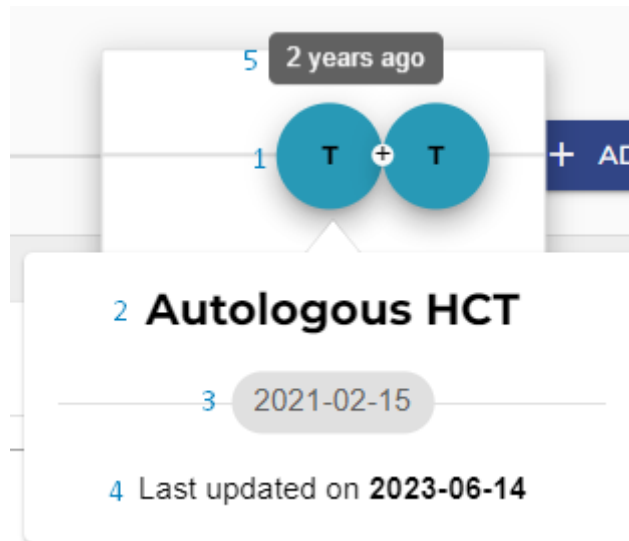


Image 45, Summary information of 2 events on the same date

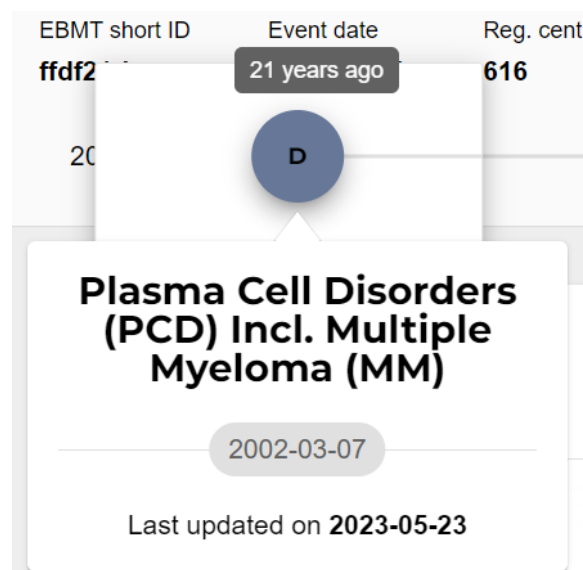


Image 46: Summary information of 1 event

Patient timeline lets users navigate through registered patients events by clicking on the events in the timeline (see [View Patient event](#)).

### Event form summary

**Event form summary** (event summary) is an area to the left of opened event form that contains some summary information about the respective event form and important buttons for the event form management. It also allows navigating between event form sections.

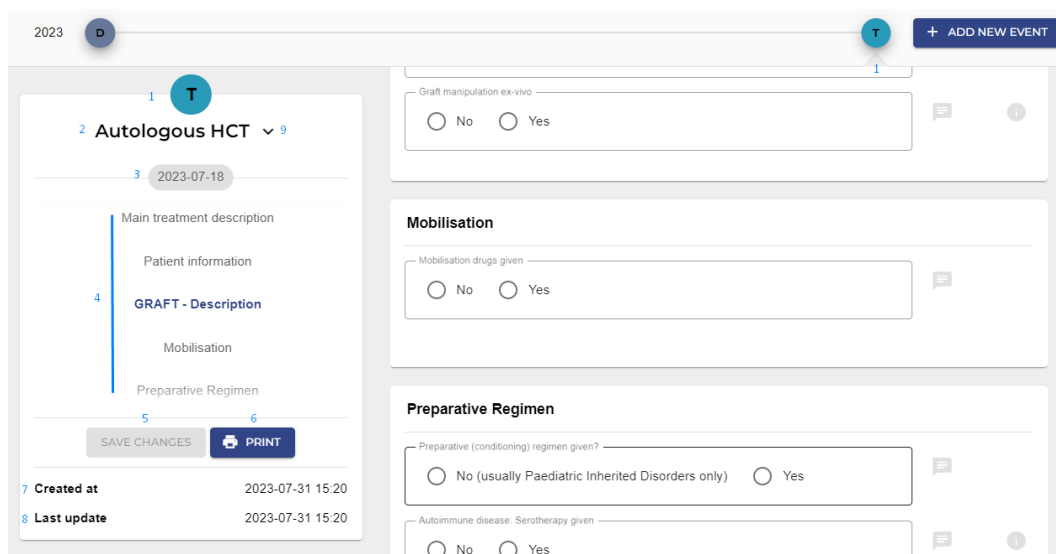


Image 47, Event form summary

It includes the following elements:

1. Coloured circle representing an event with a letter(s) representing the category of the event (e.g. D for the diagnosis, T for treatment, etc). It is equal to the one used in the Patient timeline.
2. Name of the event.
3. Date of the event.
4. Titles of the sections from the event form.

The titles of sections from the event form are listed one under another as a list. When a user scrolls through an event form, the section currently displayed in the event form is also highlighted in bold in the event form summary.

Every title of sections in the event form summary is clickable, it works similar to interactive content. Once a user hovers the mouse over the title of the section in event form summary - it becomes highlighted. Once a user clicks on it (selects), the title in the event form summary becomes highlighted and in bold and the corresponding section is being scrolled to and shown in the event form (Image 43).

5. **Save changes** button. This may be shown as active or inactive as depicted in the Table 13.
6. *Print* button

*Print* button is used to create a printable version of the event form (see [Print event](#)). This functionality will be added post go live in one of upcoming versions of EBMT Registry.


7. Created at

It is the date and time when the event was created (registered) in the EBMT Registry.

8. Last update

It is the date and time when the loaded to the screen version of the event form was last saved by an data editor in the EBMT Registry.

9. Event menu

The event menu can be called with the icon  which is to the right of the event form name. It is used to delete patient or donor events (see [Delete event](#)).



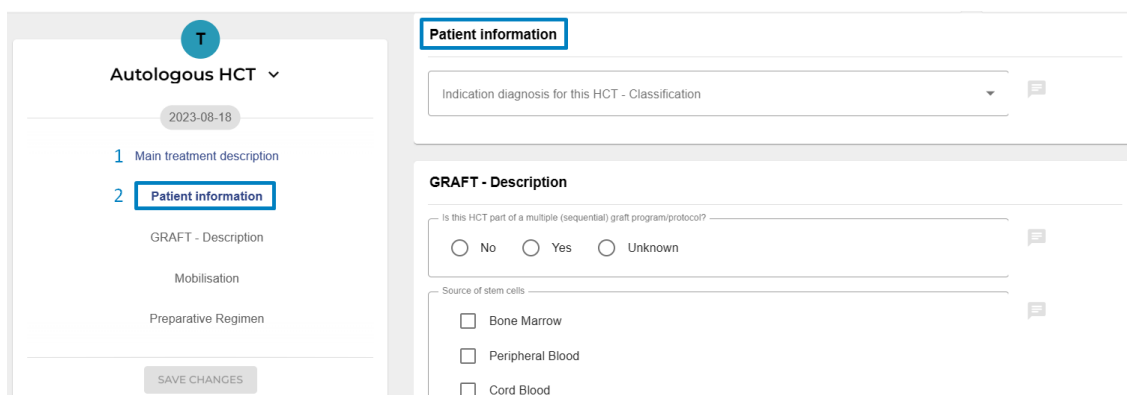


Image 48, highlighted (1) and selected (2) titles from the sections of the event form

If there are any field warning or error in any section of patient/donor event form, the corresponding icon will also be shown next to each title of the section (see more details in [Field warnings](#) and [Field errors](#))

*Save changes* button may be shown in active or inactive mode as described in a table below



Button	Description
	Active <i>Save changes</i> button signifies that there were some changes done in the currently opened event form by data editor. If the user clicks the button, the changes will be saved to the database.
	Inactive <i>Save changes</i> button signifies that the user role does not allow editing event form and saving changes (e.g. data viewer); or there were no changes done in the currently opened event form by the data editor.  Inactive button cannot be clicked.

Table 13, views of the save changes-button

## Event form

**Event form** corresponds to the Data Collection Form of the respective event with some adjustments due to electronic format and EBMT Registry design. Patient/Donor **event form** contains a series of data fields (questions). It provides a structured and organised way to capture and manage information that refers to the same event in a Patient or Donor timeline.

Tables, which are reports associated with repeated measurements that are similar for multiple items, are not used for the current version of the EBMT Registry. Thus, the tables from the EBMT Data Collection Forms are represented with a group of questions.

**Data entry field** (data field) is a designated space (field) where data can be input/viewed/edited. It is designed to capture a specific piece of information. More details on data fields can be found in the [Data entry](#) section.

Data fields are grouped by topic, similar to sections in the EBMT Data Collection Forms; in event forms, this is visually represented as a group of fields displayed on the same white square background. Each section is displayed in a separate white square background.

There are usually used titles for each section, which is also reflected in the event form summary.

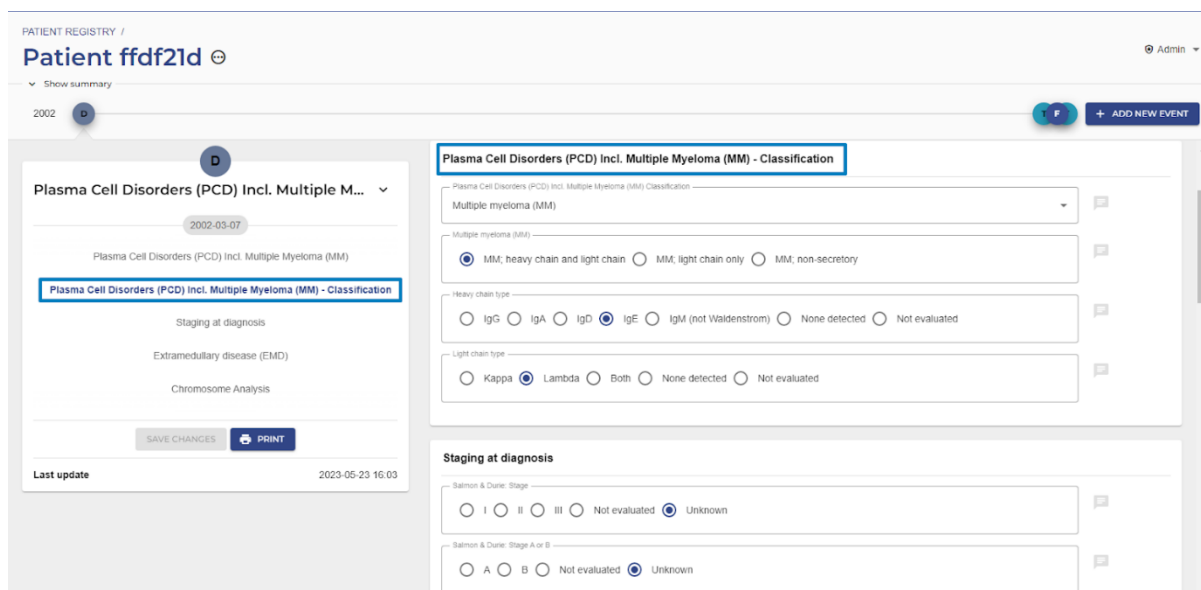


Image 49, data entry view with titles highlighted

Due to the high number of data fields within an event form, users need to scroll through the event form to navigate, or use the Event form summary to open the required section of the form.

Event forms are versioned, which means that the EBMT Registry keeps track of changes saved (e.g. user, who saved changes, date, time). It is recorded in the [audit trail](#).

When a user opens an event form, the EBMT Registry loads the latest saved version of this event form. Event form is displayed identically both for data editors and data viewers: users are able to view and manually edit values, but all such changes remain purely visual until they are saved. Any changes are recorded and saved to the database only when a Data editor saves changes - by clicking the active *Save changes* button. The system will then create a new form version that will become the most recent event form version.

Important: If the data editor leaves the event form without saving it or the [user session](#) expires, all unsaved entered data or changes will be lost and not recorded in the database or audit trail. Thus it is important to save changes done in the event form before a user:

- Navigates away from this particular event form (e.g. to other patient events or to other parts of the EBMT Registry)
- Leaves web browser tab with unsaved edited event form in the EBMT Registry
- Closes web browser tab or web browser with unsaved edited event form in the EBMT Registry
- Switches off computer
- Leaves the EBMT Registry web page without activity for 20 minutes or more (see [User session](#))

If Data viewers try to edit any event form, such changes cannot be saved to the database - they will be lost when the web page is reloaded.

### Possible editing conflicts

If two or more users are opening any patient or donor event form at the same time or with 15 minutes difference, the EBMT Registry will show a [warning](#), notifying them about **possible editing conflicts**. It is important to note that if the same form is opened or edited by multiple users, the user that presses the *Save changes* button last will create the latest event form version; this means that data entered by other users will be lost, and only the data as displayed on the main screen of this last user will be saved to the database. This is a crucial point to remember if multiple users open or edit the same form.

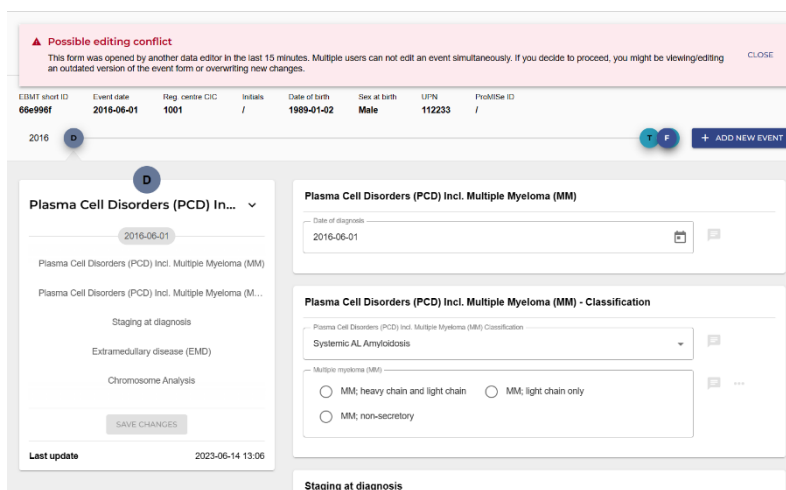


Image 50, the message shown in case of a possible editing conflict

Note: It is recommended that the users avoid situations of potential editing conflicts and return to such event records later.

#### Practical example:

- User A and User B open the same patient event form at the same time at 12:00 (or within 10 minutes of each other). The system shows a warning about a possible editing conflict. The event form is loaded on each user screen and looks exactly the same.
- User A enters data into data field 1, then presses the *Save changes* button at 12:11. The event form version 1.0 is created in the database.
- User B leaves data field 1 empty, enters data into data field 2 and data field 3, then presses the *Save changes* button at 12:15. The event version 2.0 replaces (overwrites) the event version 1.0 in the database.
- The information displayed on the User B screen will be captured in the database. The changes to data field 1 made by User A are lost, as version 1.0 has been overwritten by event version 2.0.
- Any user who enters this patient event form from 12:16 onwards will see that data field 1 is empty and data fields 2 and 3 are as entered by User B.

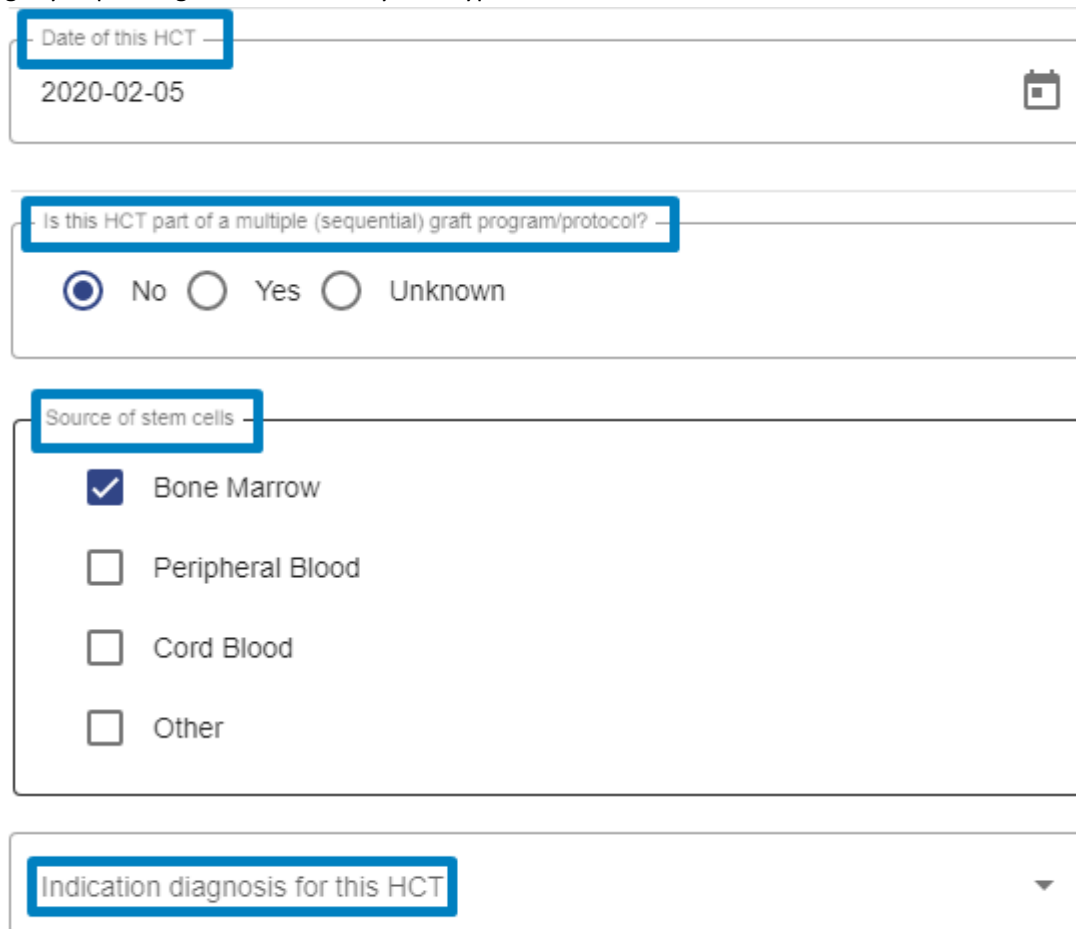
#### Hidden patient events

There are cases when patient event(s) need to be temporarily hidden from other EBMT Registry users and should be visible only to the reporting centre. This functionality will be added in upcoming versions of the EBMT Registry and it will be explained once more details are available.

## Data entry field

Data field has the following elements:

1. **Label** describes in short what data should be provided in the data field. Label design differs slightly depending on the data entry field type.



The image shows four data entry fields, each with a blue box highlighting its label:

- Date of this HCT**: A date input field containing "2020-02-05" and a calendar icon on the right.
- Is this HCT part of a multiple (sequential) graft program/protocol?**: A radio button field with three options: "No" (selected), "Yes", and "Unknown".
- Source of stem cells**: A checkbox field with four options: "Bone Marrow" (checked), "Peripheral Blood", "Cord Blood", and "Other".
- Indication diagnosis for this HCT**: A dropdown menu.

Image 51, labels in an event for data entry

2. Area to enter data or answer options to select from (see [Data entry field types](#))
3. Help **text** - some of the fields also have help text; it provides some extra details, such as the data to be entered into the data field.

The following icons may be shown to the right in a data entry field:



The image shows a data entry field for "Early graft loss" with radio buttons for "No" and "Yes". To the right of the field are three icons: a speech bubble (1), three dots (2), and a question mark (3). Below the icons are the numbers 1, 2, and 3.

Image 52, items shown next to data entry fields

1. Data query icon
2. Three dots icon to mark the data field menu, it is used to mark that the answer is [unknown/not evaluated](#).

Note: The data field menu icon is shown only for data fields, where it is possible to indicate [unknown, not evaluated and/or ongoing status](#). If the icon is not visible, this means that for this data field, it is impossible to select any of these statuses.

- Hint - help text that is not shown by default. It appears when a user hovers a mouse or cursor over the information icon to the right of the data field.

The screenshot shows a data entry form for 'First relapse'. The question is 'Was there a relapse/progression or significant worsening of organ function related to the primary disease after HCT?'. There are three radio button options: 'No' (selected), 'Continuous progression since HCT', and 'Yes'. To the right of the form is a three-dot menu icon and a grey box that says 'Detected by any method'.

Image 53, example of a hint

### Mandatory fields

Most areas are considered to be mandatory for completion in the data collection form, and a few may be optional. Optional fields are always marked. Data items should be filled in if specifically stated in the definition.

Some key data fields will also be configured to show a warning or error if left blank.

### Unknown/Not evaluated/Ongoing status

For some data fields it is possible to indicate that information is unknown or not evaluated, or the date is not known because the process was not finished (ongoing).

There is a three-dot icon to the right in some data entry fields to mark the data field menu (see screenshot below). The data field menu is a dropdown that includes one or more options that vary depending on a data field e.g. not evaluated, unknown, ongoing.

The screenshot shows a data entry form for 'Best Response'. It has two input fields: 'Best clinical/biological response after HCT' and 'Date best response first observed'. To the right of the second field is a three-dot menu icon. A dropdown menu is open, showing two options: 'Mark as Not evaluated' and 'Mark as Unknown'.

Image 54, marking a field as not evaluated or unknown

It is used when needed to state that information is not available and cannot be entered into the database, thus assigning this status to a data field. When a data editor selects an answer option from the data field menu, the field is marked with the respective status.

The screenshot shows a data entry form for 'Not evaluated'. The input field contains the text 'Percentage of chimerism'. To the right of the field is a three-dot menu icon and a grey box with a close icon.

Image 55, example of what a not evaluated field looks like after selecting 'Not evaluated'

In case it was done by mistake or information becomes available at a later stage, and data editors may remove such status from this data field:

- For fields previously marked as *Unknown*, users can enter the field value and unknown status will be removed automatically or they can remove this status through the data field menu, clicking *Mark as Normal*.

The screenshot shows a data entry form for 'Unkown'. It has two input fields: 'Disease status at the last assessment before this follow-up or date of death' and 'Was the disease detected by any method?'. The second field has three radio button options: 'No', 'Yes', and 'Not evaluated since last main treatment (HCT/CT)'. To the right of the form is a three-dot menu icon. A dropdown menu is open, showing one option: 'Mark as Normal'.

Image 56, removing the 'unknown' status

- For fields marked as *Not evaluated*, users should open the data field menu and click *Mark as Normal* to remove the Not evaluated status and, enable editing, and then enter field value if needed.



Image 57, removing the 'not evaluated' status

Ongoing status may be indicated for some date fields as shown in the screenshot below:

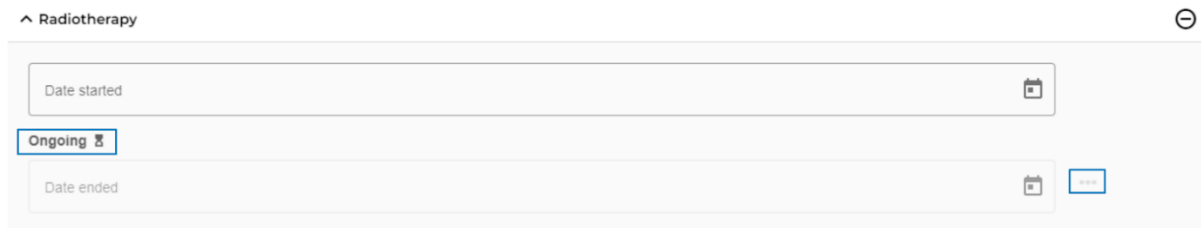


Image 58, ongoing status on a data entry field

## Data entry field types

Below is the short summary and some details on data entry fields used for online data entry. There are different types of inputs used for data fields in the EBMT Registry.

### 1. Drop-down

Drop-down is mostly used for questions with more than three answer options. The answer options will appear after clicking the field. An option can be selected from the list. For long lists, please scroll to navigate through and see all the items. Some of the drop-down lists also have a search field. In this case, it is possible to type the text on the field and obtain suggestions from the list of options available.

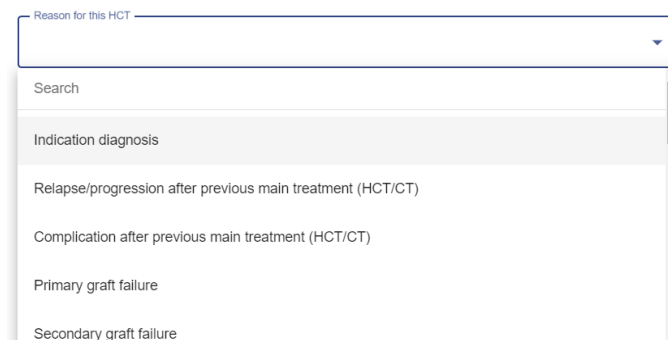


Image 59, example of a dropdown menu

### 2. Radio buttons

**Radio buttons** are used for questions where there are a few options available, but only one option can be selected. The question can be filled in by clicking the dot before the answer.

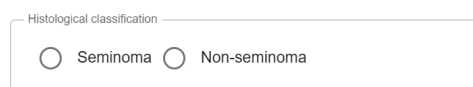


Image 60, example of radio buttons

**Important:** Radio button can be unselected if needed.

### 3. Check-boxes

**Check-boxes** are used for questions where more than one option can be selected at the same time. Check-boxes can be selected and unselected if needed.



Image 61, example of check boxes

### 4. Dates

All dates in the EBMT Registry are in YYYY-MM-DD format, where YYYY represents 4 number digits of the year, MM - 2 number digits of the month, DD - 2 number digits for the day of the month. Date fields have calendar graphics on the right.

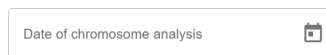
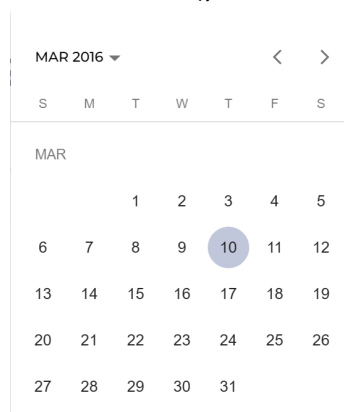


Image 62, example of a date field

Users can enter the date manually by typing it in the format YYYY-MM-DD or click the calendar graphics (▼) to open the calendar window and select the date (year, month and date).



MAR 2016							<	>
S	M	T	W	T	F	S		
			1	2	3	4	5	
6	7	8	9	10	11	12		
13	14	15	16	17	18	19		
20	21	22	23	24	25	26		
27	28	29	30	31				

Image 63, calendar view after clicking the date field

It is not possible to mark the date reported as approximate in the current version of EBMT Registry, thus all dates are considered as exact dates. In case the exact day of the month is unknown, or day and month is unknown, please follow the exact instructions as stated for the Data Collection Forms completion guidelines available at EBMT website.

In rare cases, indicating a **partial date** (e.g. Patient date of birth) is possible. In this case, another date field format is used, allowing a user via separate dropdown to specify year only, or year and month, or year and month and day.

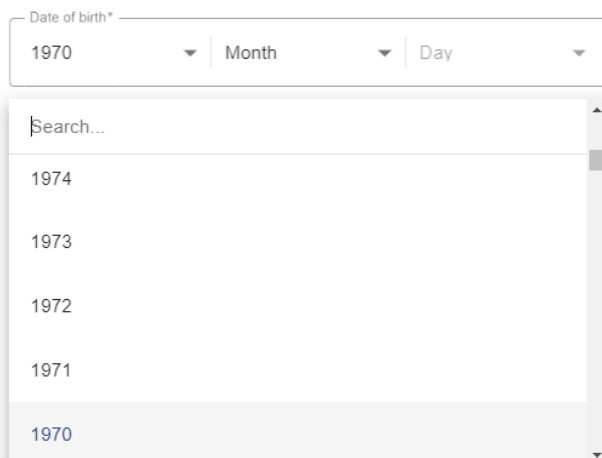


Image 64, example for adding a partial date

### 5. Text

Text fields in the EBMT Registry accept both text and numbers. Text boxes that specify Other answer options in the forms must only be used if no alternative from the dropdown or radio buttons is available. It is mandatory to answer in English, as other languages can create codification problems with letters not recognised by the system.



Image 65, example of a text box field

### 6. Calculated fields


Calculated fields are quite rare and are used to perform calculations such as the exact age at the time of an event. These calculations are done based on the information entered into the database in previous forms. Calculated fields cannot be edited.



Image 66, example of a calculated field

If the value in the data field is shown wrongly, this can happen due to a mistake in the date of birth or date of the event registered in the EBMT Registry . Please check both data fields.

### 7. Remote field

Remote fields in the EBMT Registry are marked with the  icon, it is a data field (question) answered in the earlier submitted forms that is repeated in subsequent forms. This type of field is not available for editing. If the data editor notices that the data value is incorrect in the remote field, they need to find the form where it was initially entered (source field) and correct it.

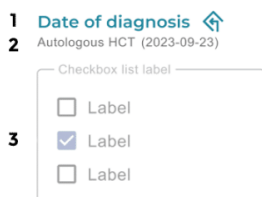


Image 67, Remote field



Remote fields are shown with the following information:

1. Name of the data field (label).
2. Name of the event form where this data field was entered, followed by the date of the event.
3. Event field with its value.

### Dependent fields

Within one form, depending on the answer given in one data field, the dependent fields may be shown requesting some extra information to be provided (e.g. depending on the class of disease, some sub-questions need to be answered). When a user changes answer option in such main field, the dependent questions are emptied and updated.

This means if the user by mistake changes answer in the main data field that has dependent fields, the information entered into dependent field(s) will be lost. The users are advised to be careful while editing data and save the form regularly after reviewing it.

Important: there are **interdependent fields** in the database across various event forms (e.g. calculated field and remote field), and if the field value is edited in one form, the EBMT Registry cannot apply the correction automatically in all the forms it is used at one time. Nevertheless, suppose a data editor corrects the field value in the source field once the subsequent form (with dependent field) is opened. In

that case, the system will apply these changes automatically and mark affected field with the  icon.

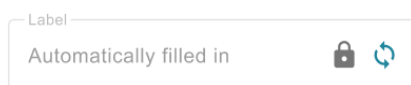



Image 68, example of a remote field that is refreshed

Updates to the affected field(s) are applied automatically, but a data editor has to click the *Save changes* button so that these changes are saved into the database. To reinforce that a user needs to save changes,

the  icon is also shown next to the *Save changes* button in the Event form summary section. It will also be logged in the audit trail.

### Repeating group of question


Repeating group of questions is a set of data entry fields (questions) that are repeated multiple times within a single data entry form (event form).

A button for *adding* the whole group of questions is often used in case it is not known the exact number of repetitions the user needs to report data is not known. Such a button is placed at the end of the last added group of questions. It has **+ Add** at the beginning of its name.





Image 69, questions in a repeating group

The group of questions may also be removed (deleted) with the help of *remove* button icon  to the right from the group of questions title.

**Important:** Once the user deletes the group of questions, the data that was entered into there is deleted and this action is not reversible. That is why users are advised to be careful and check that there is no data to be lost by this action.

For user convenience, each group of questions may be shown in full view or compact (collapsed) view to manage screen space. Users can use arrows (Table 14) to the left from the Repeated group name, which are toggle buttons to switch between these views.



Image 70, collapsed and expanded questions in a repeating group






Icon	Description
	Repeated group of questions is shown in full view, which means there are shown all its data entry fields and values, if any. Once a user presses this button, it switches to collapsed view.
	Repeated group of questions is shown in a collapsed view, which means there is only the title of the group of questions. Data entry fields and their values, if any, are not visible to free more space for other data fields and information on the user screen. Once a user presses this button, it switches to full view.

Table 14, icons used in repeating groups of questions

**Do not confuse:**

- the  icon button deletes a group of questions and enters into these fields data, while

- the  and/or  icon buttons are hiding/unhiding a group of questions on the user main screen (no data is deleted and it remains in the event form).

## Inactive data entry fields


Some data fields may be set as inactive to mark that they are irrelevant, and data editors do not need to enter information into these fields.

Nevertheless, all information submitted in deactivated fields (when they were active) remains in the database and is shown in the patient/donor event form as legacy data (historical data).


Inactive data fields are not shown to users unless they contain some legacy data.

## Delayed migration status

Since data migration from previously used systems will happen in stages, in the current version of the EBMT Registry, users will see a notification in the affected data field(s) to mark that the field value has not been migrated yet. Any field type may have such a status.

Data fields with delayed migration status are marked with the  icon. Once the migration is done, the data field value (if any) will appear, and the delayed migration status will be removed from the data field.

Delayed migration 



A screenshot of a data field with a delayed migration status. The field is a rectangular box with a light gray border. Inside the box, the text "Stated question" is displayed in a dark gray font. To the right of the text, there is a small downward-pointing triangle icon, indicating a dropdown menu. Above the box, the text "Delayed migration" is followed by a small icon consisting of three dots and a right-pointing arrow.

Image 71, a question for which migration of data is still pending

**Important:** These fields are editable as any other field (except remote and calculated data fields). If data editor users enter the field value before the migration happens, it is recorded as the latest registered data field value. Data field value from migration will be logged in the audit trail as historical data once the migration is complete.

## System notifications and data check

In the current version of the EBMT Registry, the system notifications are implemented in various ways to support the user and provide adequate support while using the system. Here are some of the most common ones:

**Success notifications** are displayed when an action is completed (e.g. when a user saves changes in the event form, thereby creating a new version in the system). It is usually a short message on a dark grey background, shown for a few seconds at the bottom of the user web page and then automatically disappears, allowing the user to continue using the application.

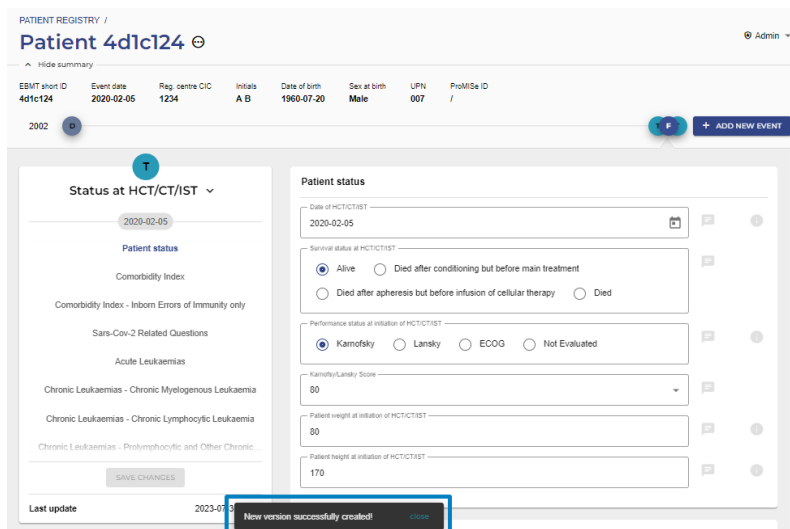


Image 72, an event with success screen visible at the bottom

**System error notifications** are displayed when an action fails, such as when a user tries to access the data of a patient who is not in the user's context. It is usually a modal window with text explaining the issue.

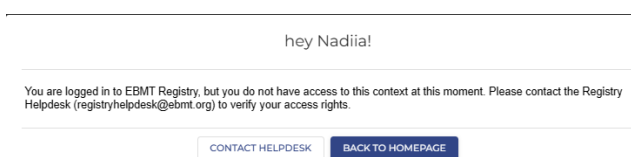


Image 73, example of an error message

**Note:** [Field errors](#) are different from system errors, they are described further in this section.

**Warning notifications** are displayed when there is a potential issue that needs to be addressed, such as when a data editor is entering a patient or donor that another data editor opened within the last 15 minutes. The system will warn the user about possible editing conflicts. This type of notification is shown in the interface next to the element it refers to.

**Note:** The [field warning](#) has a slightly different representation in the interface, and they are described in detail in the [Automated data check](#) section.

**Confirmation notifications** are usually displayed in a modal window. They typically contain a message explaining the action to be performed and asking the user to confirm or cancel the action. They often have two options: one for confirming the action and one for cancelling it.

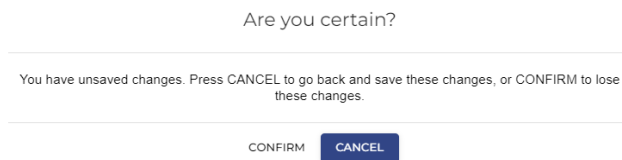


Image 74, a warning for unsaved changes

Some confirmation dialogues may also include additional options, such as stating a reason for the specific action being confirmed (e.g. stating a reason for making a change in an already submitted event form).

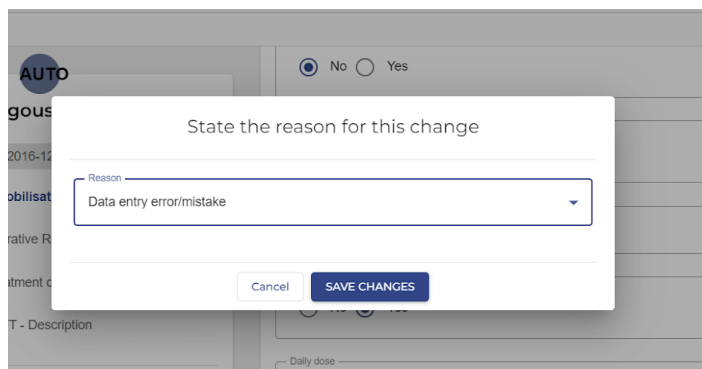


Image 75, the popup to enter the reason for changing previously saved data

## Automated data check

The automated data check, warning and error messages are important features of the EBMT Registry and are designed to improve data quality and to prevent mistakes.

With an **automated data check**, the system automatically verifies the data entered by users, comparing it to established standards (validation rules and reference values) or previously entered data, flagging any inconsistencies or errors. This helps prevent common mistakes such as typos, missing information, incorrect formatting, etc.

The automated data check is set up by the EBMT Registry team and is not visible to the end user. In case of possible issues or concerns, users should contact the EBMT Registry Helpdesk by emailing [registryhelpdesk@ebmt.org](mailto:registryhelpdesk@ebmt.org).

**Field warnings and error messages** are another important feature, providing real-time alerts to users about any issues or concerns that arise during data entry. Most of them do not affect or block data entry processes. However, the message will remain visible, allowing monitors and other users (data viewers and data editors) to see that the field/event form/patient data contains an unexpected value.

Practical example: for values that are expected to fall within set ranges or specific answers, a warning/error message may be displayed next to a data entry field if the entered value does not match

the range/expected value: e.g. if a value is entered in percentages higher than 100, or for negative weight or height values.

Note: The process of EBMT Registry improvements is expected to be a continuous one. This means that new validation checks, warnings and errors will be added to improve the data quality consistently and to support users in the process of data entry.

### Field warnings

Warnings are used to inform EBMT Registry users that there is an issue with the entered field value, or a missing field value. It is shown in the following way:

1. The field is highlighted in yellow;
2. There is a message text under the field to explain the warning;
3. an exclamation mark in a triangular box is shown in the right upper corner of the question group;
4. an exclamation mark in a triangular box next to the title of the event form section in the [event form summary](#).

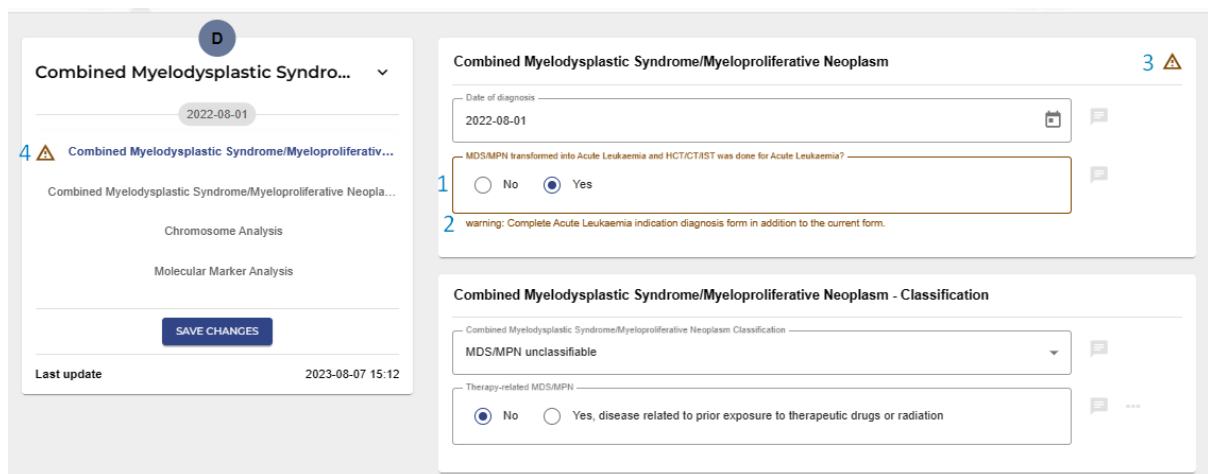


Image 76, field warnings on an event

### Field errors

Error messages are used to inform EBMT Registry users of an error in the entered field value or a missing field value. It is shown in the following way:

1. the field is highlighted in red;
2. there is a message text under the field to explain the error;
3. an exclamation mark in the circle is shown in the right upper corner of the question group;
4. an exclamation mark in the circle is next to the title of the event form section in the [event form summary](#).

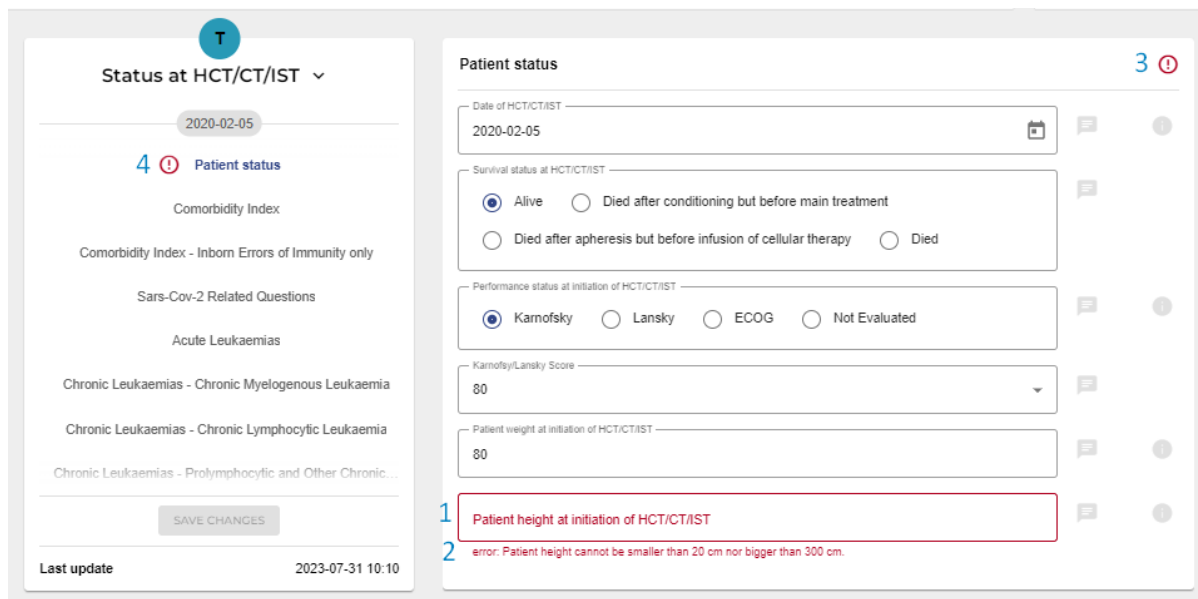


Image 77, example of a field error

Note: that there are some data fields in the EBMT Registry that must be answered and cannot be left blank. For example, the event date. The system will not allow the form to be created/saved without entering value into such a crucial field.

### Duplicate check (tentative patients)

The EBMT Registry performs the duplicate check when a user creates a new patient in the system. This ensures:

- Avoiding duplicate entries: identifying existing patient records helps prevent duplicate entries in the database. It ensures that each patient has a unique and single record, improving data management.
- Data accuracy: by highlighting potential duplicates, the application assists users and EBMT staff in reviewing and verifying patient information.

When a user enters new patient information during the patient registration process, the application performs the following steps:

1. Data validation: The application validates the entered information for completeness and correctness, ensuring that all mandatory fields are filled accurately.
2. Matching Criteria UPN (the same UPN at the same centre)
3. The application compares the entered data against existing records in the system using the predefined matching criteria (duplicate check algorithm).

**Case 1:** if the new patient UPN is identical to the UPN of an existing patient at this centre, these records are considered duplicates- creating a new patient is not allowed. The user will receive a corresponding error message and a summary of patient details (see screenshot below). The user can either cancel the new patient creation and continue working on the existing patient page, or the user can modify the data of the patient under creation and try registering it again.

4. Potential duplicates: If the application finds records that closely match the entered data, it displays a warning message. The duplicate check matching criteria include:
- Birthdate;
  - Sex at birth;
  - Blood group;
  - Rhesus factor;
  - Initials.

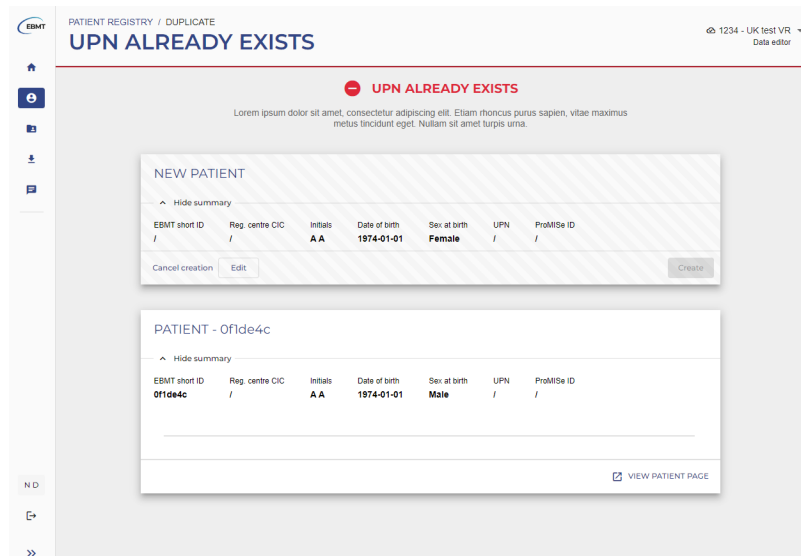


Image 78, the warning message if a duplicate UPN is entered

Note: at the go-live version, the EBMT Registry was configured to perform the duplicate check through all the patients in the database. It was already decided that in one of the upcoming versions post-go-live, the duplicate check will be limited to the patient country only: this means that the new patient data will be only compared to data of patients registered in the same country.

The duplicate check algorithm is set up in such a way that the system compares the data value of the new patient (Pn) and existing in the database patient (Pe) in the following order:

1. **Date of birth** match - this is done by progressively deepening into the comparison:

- First, the year of birth is compared;
  - If they match, the system proceeds to compare the next parameter;
  - If they don't match, Pe and Pn are not considered being duplicates (comparison stops).
- Second, the month of birth is compared:
  - If it is specified for both patients, proceed to compare the next parameter;
  - If it is specified for both patients and doesn't match, Pe and Pn are not considered duplicates (comparison stops).
  - If in one or both patients, the month of birth is not specified in one or both patients, the system will consider them matching and compare the following parameter.
- Third, the day of birth is compared:
  - If it is specified for both patients and match, the rule is satisfied. The system proceeds to compare the next parameter.



- If it is specified for both patients and don't match, Pe and Pn are not considerate being duplicates (comparison stops).
- If in one or both patients the day of birth is not specified, the system will consider them matching and proceed to compare the next parameter.

## 2. Sex at birth match

- If in one or both patients records the sex is not specified (patients registered through the previous system sometimes do not have this data), the system will consider them matching and proceed to compare the next parameter.
- If it is specified for both patients and don't match, Pe and Pn are not considerate being duplicates (comparison stops).

## 3. Blood group match

- If the blood group is not specified for one patient, the system will consider them matching and proceed to compare the next parameter.
- If it is specified for both patients and don't match, Pe and Pn are not considerate being duplicates (comparison stops).

## 4. Rhesus factors match:

- If in one or both patients records the rhesus factor is not specified (patients registered through the previous system sometimes do not have this data), the system will consider them matching and proceed to compare the next parameter.
- If it is specified for both patients and doesn't match, Pe and Pn are not considered duplicates (comparison stops).

## 5. Initials match

- If it is specified for both patients and match, the match should be exact, disregarding the lower/upper case: e.g. A/G match a/g, while NN/S do not match N/S.
- If it is specified for both patients and don't match, patients are not considerate being duplicates.
- If in one or both patients the initials are not specified, the system will consider them matching and proceed to compare the next parameter.

The following cases may arise in case EBMT Registry identifies possible duplicate(s):

**Case 2:** The user is trying to create a patient that is a possible duplicate of an existing patient. The user has access to existing patient data and thus can review data and check whether patients are duplicates or not. The EBMT Registry lists potential duplicates for the user's review (see screenshot below).

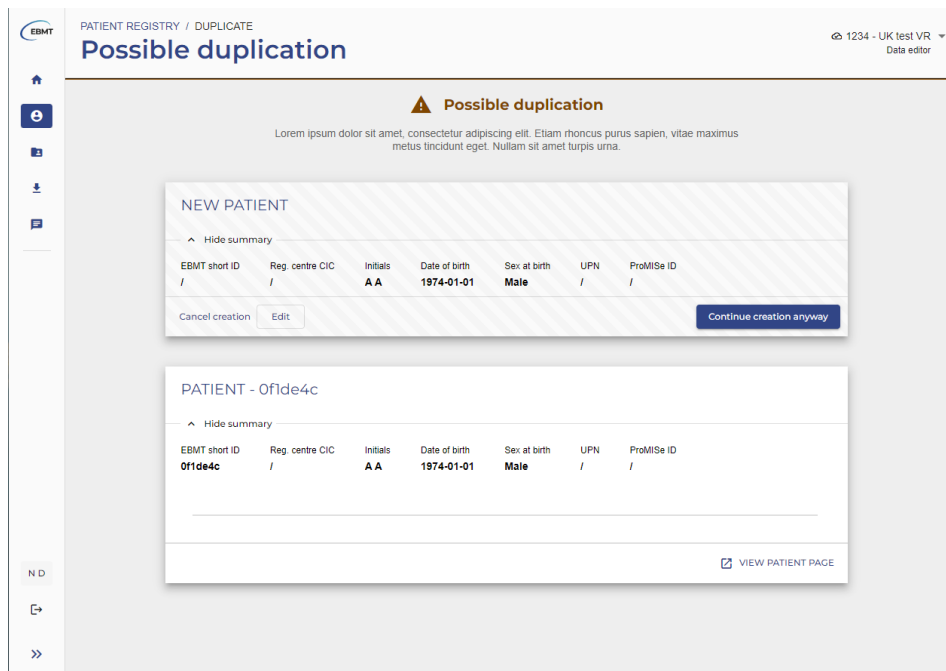


Image 79, the warning for a possibly duplicate patient where the user has access to the other patient

Possible actions for the user:

**Review:** The user carefully examines the potential duplicate records to determine whether they correspond to the same patient or, if indeed, separate individuals.

**Final action:** Based on the user's evaluation, the application allows the user to either:

- proceed with the registration of a new patient (by clicking *Continue creation anyway*): the new patient will be registered but marked as tentative pending administrator review;
- cancel the new patient creation (by clicking *Cancel creation*) and select an existing patient record to register or edit data.

**Case 3:** The user is trying to create a patient that is a possible duplicate of an existing patient. The user does not have access to the data of an existing patient (this patient is not in the user [Context](#)) and thus cannot review data and check if the patients are duplicates or not. The EBMT Registry shows the respective warning (see screenshot below). The data of patients outside of the user context are not visible.

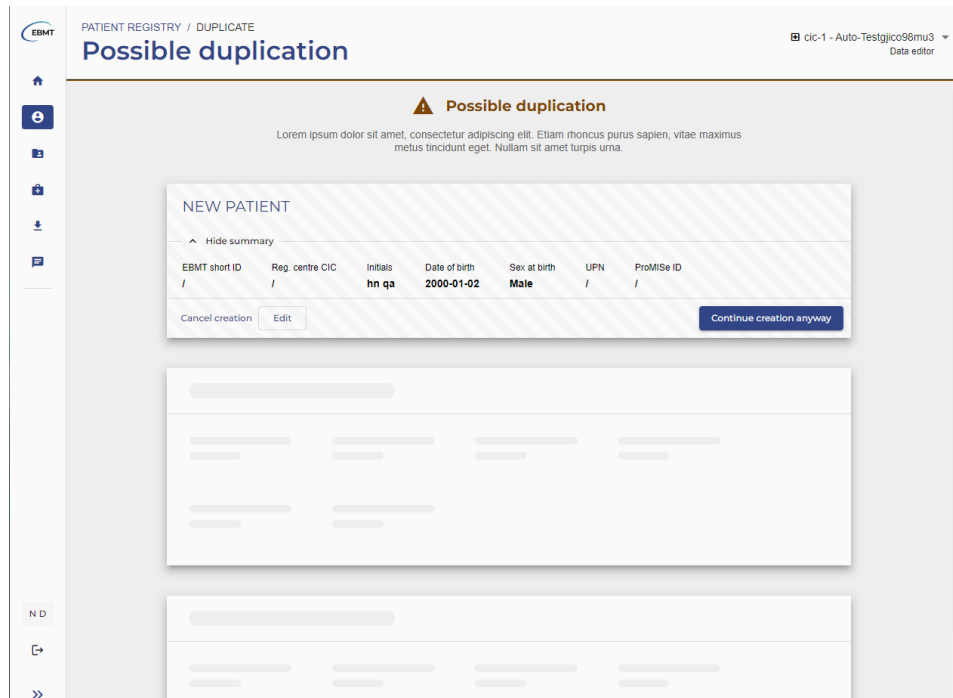


Image 80, the warning for a possible duplicate patient where the user does not have access to the possible duplicate

Possible actions for the user:

Based on the user's evaluation, the application allows the user to either:

- proceed with the registration of a new patient (by clicking *Continue creation anyway*): the new patient will be registered but marked as tentative pending Administrator review;
- cancel new patient creation (by clicking *Cancel creation*).

If the EBMT Registry does not suspect a new patient under creation as a possible duplicate, the patient is registered in the system and appears immediately in the patient overview list.

## Access to the EBMT Registry: all users HOW TO

Here is simple step-by-step for a user to get access to the EBMT Registry:

- 1. Submit the *EBMT Registry User Account Request form* to the EBMT Registry Helpdesk by emailing [registryhelpdesk@ebmt.org](mailto:registryhelpdesk@ebmt.org).**

It is important to note that the user role will be already indicated at this stage. The form must be properly filled in and signed by the PI of the centre or VR.

If a user requires access to multiple contexts, the form needs to be filled in per each context.

- 2. Complete the EBMT Registry training in the EBMT E-learning platform.**

EBMT will activate access to the EBMT Registry only for the individuals who have successfully completed the specifically designed training and passed the exam in the EBMT E-learning. This is in order to ensure that the users are able to work with the new web application and the database.

Access to the E-learning training will be provided to all users who submit the *EBMT Registry User Account Request form*.

In case a user requires access to multiple contexts with different roles, the following should be taken into account:

Completed Data viewer training - is valid only for users to be granted a Data viewer role.

Completed Data editor training - is valid for both Data viewer and Data editor roles.

Only certificates on successful completion of the respective course in the EBMT E-learning will be recognised and considered while setting a user account in the EBMT Registry.

Additional online or face-to-face training course(s), questions and answers sessions, and other events provided by EBMT, National Registries or other stakeholders may be organised to support the users but cannot substitute the E-learning training.

It should be expected that new functionalities will be developed and added to the EBMT Registry application in the future, which will be announced to the EBMT members and stakeholders accordingly. In case of major changes, the users might be asked to undergo additional specific training and pass exams.

**Note:** the EBMT will require some time to process the confirmation on successful completion of the EBMT E-learning course and for the administrator to create/activate the user in the system and link to a correct context. Until this is completed, when a user Signs up or Signs in to the EBMT Registry, they may experience the following problems:

- Warning message that there is no active user with such email; or
- Required centre/VR is not shown in the Context menu (as requested in the *EBMT Registry User Account Request form*).

- 3. Sign up and Sign in to the EBMT Registry application.**

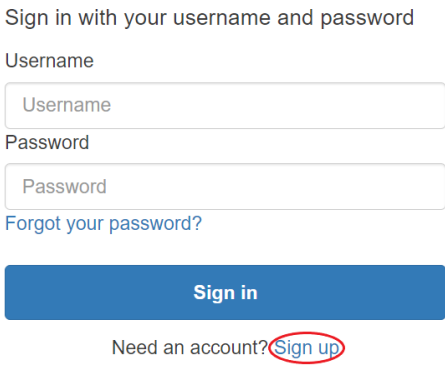
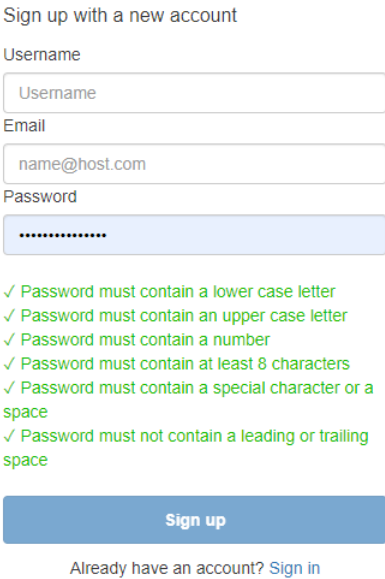
The sign in (log in) to the EBMT Registry web-based application is currently done through the *AWS Cognito* service, which is an external service to manage the identity and authentication of users.

All [Users](#) need to set up and pass 2-factor authentication, which means that every time they want to sign in to the EBMT Registry, they not only enter their login and password but also need to confirm the entry through an additional [MFA](#) authenticator program.

Details on [Sign up](#), [Setting up the MFA](#), [Sign in](#) and other related processes will be further explained in the current section of the Manual.

## First time sign up - how to create login and password

Please follow the following step-by-step to create a username and password to access the EBMT Registry for the first time:

Step	User actions	EBMT Registry
1	Open the app in your browser.	The regular Log in page opens.  
2	Click the <b>Sign up</b> text button at the bottom of the form.	The <b>Sign up with a new account</b> form opens.  
3	Fill-in the <b>Sign up with a new account</b> form: <ul style="list-style-type: none"> <li>● Create <a href="#">Username</a>;</li> <li>● Input <a href="#">Email</a> (it must be the same email as in the <i>EBMT Registry User Account Request form</i>);</li> <li>● Create <a href="#">Password</a>, check that password requirements are met</li> </ul>	The <b>Confirm your account</b> form opens.

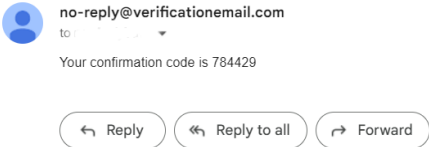
	<p>and thus all highlighted in green; and</p> <ul style="list-style-type: none"> <li>• Click the <b>Sign up</b> button.</li> </ul>	
	<div style="text-align: center;"> <h3>Confirm your account</h3> <p>We have sent a code by email to t***@e***. Enter it below to confirm your account.</p> <p>Verification code <input type="text"/></p> <p><b>Confirm account</b></p> <p>Didn't receive a code? <a href="#">Send a new code</a></p> </div>	
<p>4</p>	<p>Check the mailbox specified in Step 2. There will be a new email from <a href="mailto:no-reply@verificationemail.com">no-reply@verificationemail.com</a> with the confirmation code that contains six digits. If you cannot find such an email in your Inbox, please check the Spam folder.</p> <div style="text-align: center;">  <p>no-reply@verificationemail.com to: ... Your confirmation code is 784429</p> <p>← Reply   ← Reply to all   → Forward</p> </div> <p>If the mail still has not arrived after a few minutes, please go to the <i>Confirm your account</i> window and press <b>Send a new code</b> text button, which is located at the bottom of this modal window. The system will send a new code to the entered email address.</p>	
<p>5</p>	<p>Enter the confirmation code from the email to <b>Confirm your account</b> form and click the <b>Confirm account</b> button.</p> <p><b>Important: Sign up confirmation code is valid for 24 hours. After that, it expires. Please make sure to enter received code into the required field of <b>Confirm your account</b> form and complete the Sign up process at your earliest and before this deadline.</b></p>	<p>If the code is entered correctly, the system will proceed to <a href="#">Set up MFA</a> process.</p> <p>If the code is entered incorrectly, the system will show an error: <i>Invalid verification code provided, please try again.</i></p> <p>Try entering the code again or request a new code to be sent with <b>Send a new code</b> text button.</p>

Table 15, steps on setting up your credentials

## Set up MFA

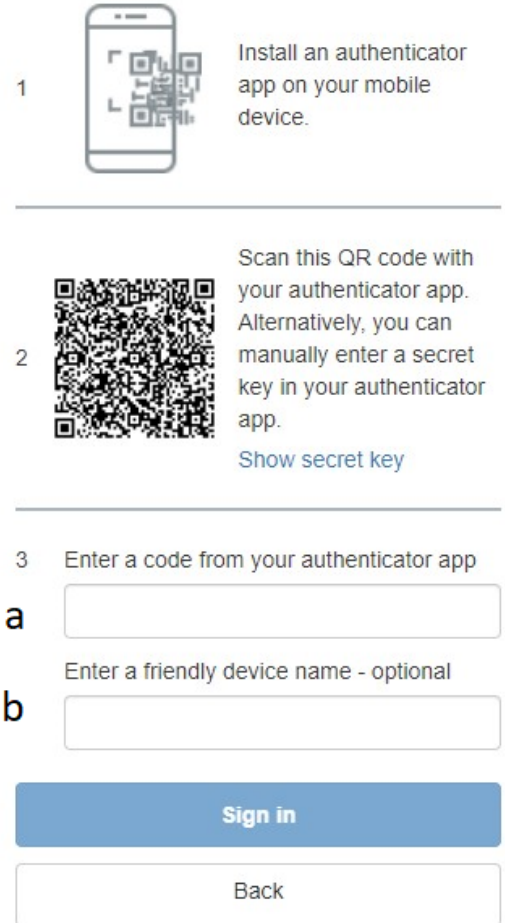
Instructions on setting up the [authenticator application MFA](#) are displayed on the screen (Image #). It includes the following steps:


1. Install an authenticator application on your mobile device.  
OR  
Install an authenticator application on your computer.

**Important:** remember that this device must always be available when a user tries to sign in to the EBMT Registry. It is not possible to use different devices.


2. Scan the QR code displayed on the screen (Image 76) with your authenticator app - this will automatically add your account to the authenticator app.  
OR  
Alternatively, you can click the **Show secret key** text button and manually enter the shown secret key (combination of letters and numbers) into your authenticator app. Depending on the app, you might also be asked to enter the name of the account and the type of code.

### Set up authenticator app MFA



1  Install an authenticator app on your mobile device.

---

2  Scan this QR code with your authenticator app. Alternatively, you can manually enter a secret key in your authenticator app.  
[Show secret key](#)

---

3 Enter a code from your authenticator app

**a**

Enter a friendly device name - optional

**b**

**Sign in**

Back

Image 81, setting up authenticator app MFA

3. a) Verify your account: once you have added your account to the authenticator app, you will need to verify it. This involves entering a code that is generated by the app into the field **a** on Image 72. This code changes every few seconds, so make sure you enter the correct code at the right time.  
b) Enter an MFA device name into the field **b** on Image 76 to remember which device you use for entering the EBMT Registry. This field is optional. If you leave it blank, you will be shown in the future instructions with default text *Please enter the code from passcode app*.
4. Click the **Sign in** button at the bottom of *Set up of authenticator application MFA* form. If the authenticator app was verified correctly and you entered the correct code, you will be signed in to the EBMT Registry and see the Dashboard.

**Note:** If the authenticator app was not verified correctly or you entered an incorrect code, you will see an error message *Invalid or expired code entered. Try again.* You can try entering the code



from your authenticator app once again, as explained in Step 3. If the sign-in failed again, try to remove the account from your authenticator app and set it up again, as explained in Step 2.

## Regular Sign in

This section explains the process of entering the EBMT Registry for the users that have already done the first time [Sign up](#) (created their username and password) and [Set up MFA](#). This means that such users have entered the EBMT Registry in the past:

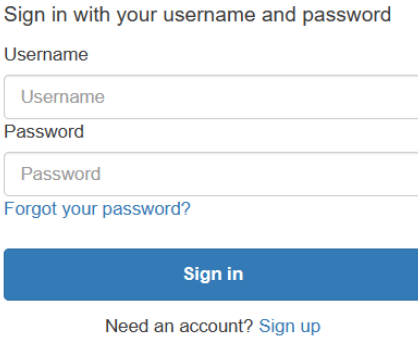
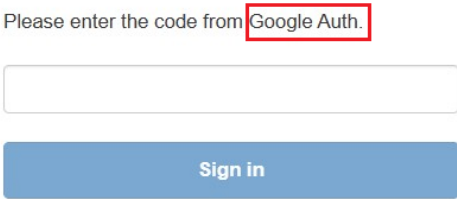
Step	User actions →	EBMT Registry
1	Open the app in your browser.	The regular Sign in page opens.
		
2	Fill-in the <i>Sign in</i> form: <b>Username</b> - you can enter here the email address or your username registered at the first time <a href="#">Sign up</a> . <b>Password</b> - enter the latest password you registered. Click the <b>Sign in</b> button.	If you entered the correct username and password, the <i>MFA Code</i> form to enter the code from your authenticator device opens.  Name of the device is displayed as registered in Step 3b of <a href="#">Set up MFA</a> .  If you entered incorrect username and/or password, the error message <i>Incorrect username or password</i> will be shown.
		
3	Enter the code from your authenticator app into <i>MFA Code</i> form and click the <b>Sign in</b> button.	If you entered a correct code, you will be signed in to the EBMT Registry and see the Dashboard.  If you entered an incorrect code, you will see an error message <i>Invalid or expired code entered. Try again</i> . You can try entering the code from your authenticator app again.

Table 16, signing in after setting up your account

Important: after five consecutive failed login attempts, regardless of the reason (wrong username, wrong password, etc), there is an enforced lockout time for that user. A lockout time is a period in which the user cannot make any more attempts for authentication. Users should not try to sign in for a minimum of 15 minutes, after that, the user can do a normal sign-in attempt again or reset their password through the *Forgot your password* functionality. If the issue still persists, users should contact the Registry Helpdesk [registryhelpdesk@ebmt.org](mailto:registryhelpdesk@ebmt.org).

Possible error messages:	Error related to topic	How to resolve
No active user with this email found in the system	<a href="#">Inactive user</a>	<ol style="list-style-type: none"> <li>1. Make sure you have submitted an <i>EBMT Registry User Account Request form</i> with the same <a href="#">email</a> address.</li> <li>2. Make sure you have successfully completed the EBMT E-learning training.</li> <li>3. Contact the EBMT Registry Helpdesk providing details of the user experiencing the problem (user registered <a href="#">email</a> address must be indicated).</li> </ol>
No context assigned to a user	<a href="#">Context</a> or <a href="#">Inactive Centre/VR</a>	<ol style="list-style-type: none"> <li>1. Contact the EBMT Registry Helpdesk providing details of the user experiencing the problem (user registered <a href="#">email</a> address must be indicated) and CIC number of the centre/VR.</li> </ol>

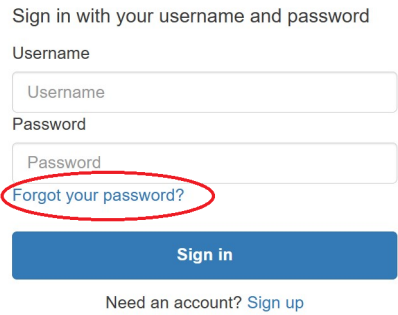
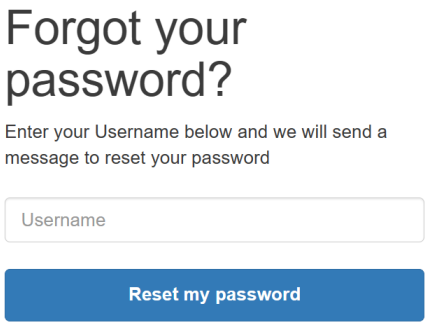
Table 17, common error messages and steps to resolve them

## Password change

Users can change their password in two ways:

1. from the EBMT Registry login page;
2. from the [User profile](#) when the user is in the EBMT Registry (signed in).

1. Here is step by step to change the password from the EBMT Registry login page:

Step	User actions	EBMT Registry
1	Open the app in your browser.	The regular <i>Sign in</i> page opens.
	 <p>Sign in with your username and password</p> <p>Username</p> <input type="text" value="Username"/> <p>Password</p> <input type="password" value="Password"/> <p><a href="#">Forgot your password?</a></p> <p><b>Sign in</b></p> <p>Need an account? <a href="#">Sign up</a></p>	
2	Click <b><i>Forgot your password?</i></b> text button at the <i>Sign in</i> page.	The <i>Forgot your password</i> page opens.
	 <p><b>Forgot your password?</b></p> <p>Enter your Username below and we will send a message to reset your password</p> <input type="text" value="Username"/> <p><b>Reset my password</b></p>	
3	Enter your Email or Username into the field at <i>Forgot your password</i> page and press <b><i>Reset my password</i></b> button.	The system will send the code for the password change to the registered email.  The <i>Change password</i> page opens.

	<p>We have sent a password reset code by email to n***@e***. Enter it below to reset your password.</p> <p><b>Code</b></p> <input type="text" value="a"/> <p><b>New Password</b></p> <input type="text" value="b"/> <p><b>Enter New Password Again</b></p> <input type="text" value="c"/> <p><b>Change Password</b></p>	
	<p>Check the mailbox specified on Step 2. There will be a new email from <a href="mailto:no-reply@verificationemail.com">no-reply@verificationemail.com</a> with the confirmation code that contains six digits. If you cannot find such an email in your Inbox, please check the Spam folder.</p> <p>no-reply@verificationemail.com to</p> <p>Your password reset code is <u>043409</u></p> <p>Reply   Reply to all   Forward</p>	
<p>4</p>	<p>Fill in fields <b>a</b>, <b>b</b> and <b>c</b> in <i>Change password</i> page:</p> <ul style="list-style-type: none"> <li>- enter the confirmation code from the email to the field <b>a</b>;</li> <li>- enter a new password to the field <b>b</b>;</li> <li>- enter a new password again to the field <b>c</b>;</li> </ul> <p>check that password requirements are met and thus all highlighted in green.</p> <p>Click the <b>Change password</b> button.</p> <p><b>Important: password reset code is valid for 1 hour only. After that it expires. Please make sure to finalise Password change/reset before this deadline.</b></p>	<p>The regular Sign in page opens.</p> <p>The new password is now saved and should be used.</p> <p>Follow the regular <a href="#">Sign in</a> process to enter the EBMT Registry.</p>

Table 18, steps after a user forgets their password for the EBMT Registry

2. When the user is signed in to the EBMT Registry they can change their password in the following way:

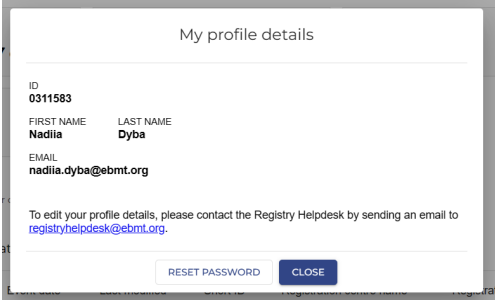
Step	User actions	EBMT Registry
1	Open <a href="#">User profile</a> at the <a href="#">Navigation menu</a> and click the <b>Reset password</b> button.	The <i>Forgot your password</i> page opens.
		
	<p>Follow the <b>Steps 2-4</b> as described above to change the password from the EBMT Registry login page.</p> <p><b>Important: password reset code is valid for 1 hour only, after that it expires. Please make sure to finalise Password change/reset before this deadline.</b></p>	

Table 19, changing the password for the EBMT Registry

## Reset MFA

Reset MFA is required in some cases, including but not limited to:

- user needs to change the MFA device or authentication application;
- previously used MFA device is not secure or lost.

Reset of MFA settings will also require the user to change both the password to the EBMT Registry and Set up MFA once again. The process for MFA reset is described in the following step by step:

Step	User actions	EBMT Registry
1	Contact the EBMT Registry Helpdesk ( <a href="mailto:registryhelpdesk@ebmt.org">registryhelpdesk@ebmt.org</a> ) to notify that the MFA device is lost or needs to be changed. Provide details.	Administrator resets users settings for MFA.  Important: MFA settings reset involves multiple parties and may take up to 7 working days.
	<p>Check the mailbox. There will be a new email from <a href="mailto:no-reply@verificationemail.com">no-reply@verificationemail.com</a> with the information as provided in the example below. If you cannot find such an email in your Inbox, please check the Spam folder.</p> <p><i>Dear,</i>  <i>Your account to the EBMT Registry has been reset by an administrator. You can log in using your original username and the temporary password below to (re-)configure MFA.</i>  <i>Username: [username]</i>  <i>Temporary password: [temporary password] (e.g. 2%vqDea0)</i>  <i>Kind regards</i></p> <p>Important: temporary password from MFA reset email is valid for 24 hours. After that, it expires. Please make sure to complete Steps 2-4 as soon as possible and before this deadline.</p>	
2	Open the app in your browser.	The regular <i>Sign in</i> page opens.
3	Enter the <b>Username</b> and <b>temporary password</b> received by email (in Step 1).	The <i>Change Password</i> page opens.
	<div style="text-align: center;"> <h3>Change Password</h3> <p>Please enter your new password below.</p> <p>New Password</p> <input type="password"/>  <p>Enter New Password Again</p> <input type="password"/>  <p><a href="#">Send</a></p> </div>	
4	Enter a new password to the fields in the <i>Change Password</i> page. Check that password requirements are met and thus all highlighted in green.	The <i>Set up an authenticator app MFA</i> window opens. Follow the <a href="#">Set up MFA</a> process.

	Click the <b>Send</b> button.	
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Table 20, resetting your multi-factor authentication

## Sign out

Signing out of a web application is essential to ensure the security and privacy of sensitive data. By signing out, the user terminates the session of the web application. This means that once logged out, the user has to go through the [Sign in](#) process, including MFA, to enter the system again.

Signing out from the EBMT Registry is essential for several reasons, including:

- **Security:** Signing out from the application ensures that sensitive medical data is protected from unauthorised access by others who may have access to the user's computer or device.
- **Privacy:** Signing out of the application helps to protect user privacy.
- **Compliance:** Signing out of the application is necessary to comply with various regulations and standards governing the handling and storage of medical data, such as HIPAA and GDPR.

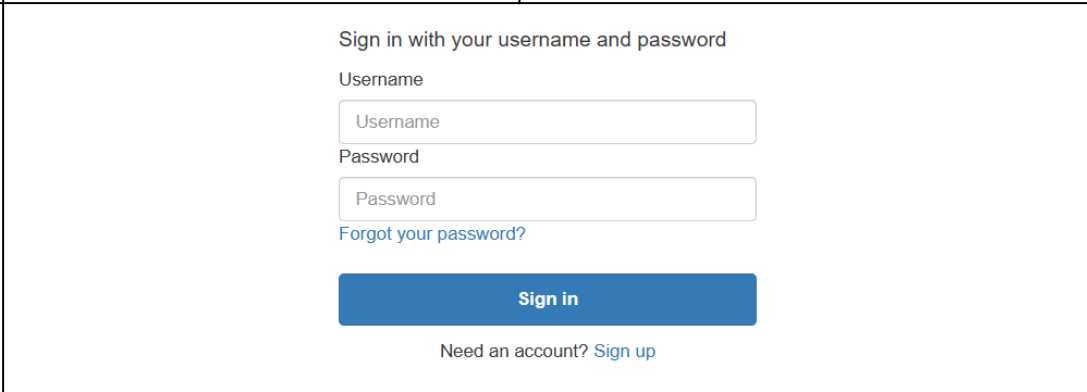
Step	User actions	EBMT Registry
1	From anywhere in the EBMT Registry, click the <i>Sign out</i> button or icon in the <a href="#">Navigation menu</a> .	The regular <i>Sign in</i> page opens.
		

Table 21, logging out

**Note:** simply closing the user's browser window or tab is not considered secure enough and does not substitute the sign out (logout) process. If a user does not sign out properly, the user's session may remain active in one of the open browser tabs, potentially allowing unauthorised access to the data.

If EBMT Registry was open in multiple tabs of the browser and the user terminates the session in one of the tabs (signs out), the information already loaded in the still open tab with EBMT Registry web app will remain visible, but upon reloading the EBMT Registry tab(s) (or any activity on the web page) the user will see the Sign in page.

If, for any reason, a user is using two or more browsers (not tabs) to work in the EBMT Registry simultaneously, The Sign-out process (session termination) should be done separately for each browser. It is not recommended, though, to work in multiple browsers to avoid confusion or editing conflicts.



### Change Context

The process below explains how to change the [Context](#) for users that have access to multiple contexts.

Step	User actions	EBMT Registry
1	From anywhere in the EBMT Registry, click the <a href="#">Context menu</a> .	Dropdown list with the list of all available for the user active contexts will be open under the Context menu.
2	Click the context you want to be opened.	The <a href="#">Dashboard</a> for the user in the selected context is loaded. The Context menu displays the name of the context and user role.

Table 22, changing contexts

## Viewing data

Once the user with access to one or multiple contexts enters the EBMT Registry, they can navigate around and view the data available within their [context](#).

Use the Navigation menu to open the Patient registry or Donor outcome registry.

Click the Patient in the [Patient Registry](#) or Donor in the [Donor outcome registry](#) to open and view the [Patient/Donor page](#), and see summary data, timeline, and events.

From the Patient page, users can also open the [Patient menu](#) to see the following information about this patient:

- Patient registration data and related details.
- Consent data - responses to EBMT Informed Consent questions.
- Studies - summary on any EBMT and non-EBMT studies the patient was/is enrolled in.
- Centres - Information on the patient registration centre as well as centres that have access to the patient record and the UPN for each of these centres.

From the Donor page, users can open the [Donor menu](#) to see the following information about this donor:

- Donor registration data and related details.
- Consent data - responses to EBMT Informed Consent questions.
- Centres - Information on the donor registration centre as well as centres that have access to the donor record and the Donor ID for each of these centres.

This section provides simplified step-by-step instructions to find and view various types of data within EBMT Registry user context for users of all roles.

### View Patient/Donor Event

Please follow the below step-by-step to access and view Patient/Donor events.

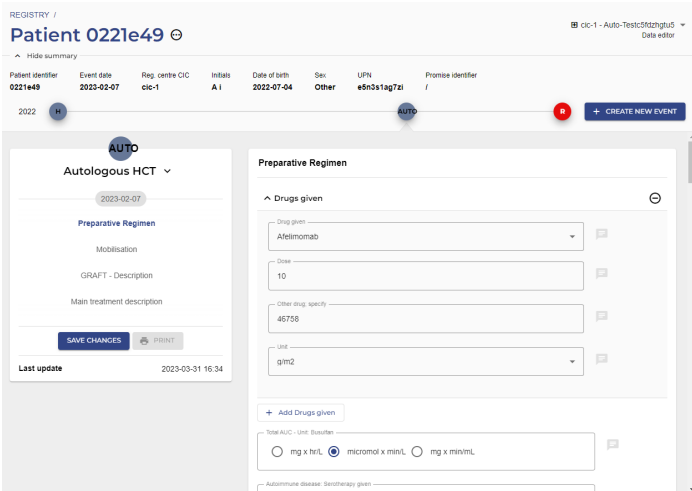
Step	User actions	EBMT Registry
1	Click on the Event in the <i>Patient/Donor timeline</i> (Patient or Donor page).	<i>Patient/Donor event form</i> and <i>Patient/Donor event form summary</i> is loaded and shown on the Main screen.
		
	<p>Patient/Donor event form includes:</p> <ul style="list-style-type: none"> <li>● Patient/Donor event form data.</li> <li>● <b>Save changes</b> button - to save any introduced changes to the event. This button is disabled for data viewers/monitors.</li> </ul>	

Table 23, viewing a patient/donor events

### Editing Patient/Donor Details

Please follow the step-by-step below to access and edit patient or donor general registration data fields and their EBMT patient ID or EBMT donor ID.

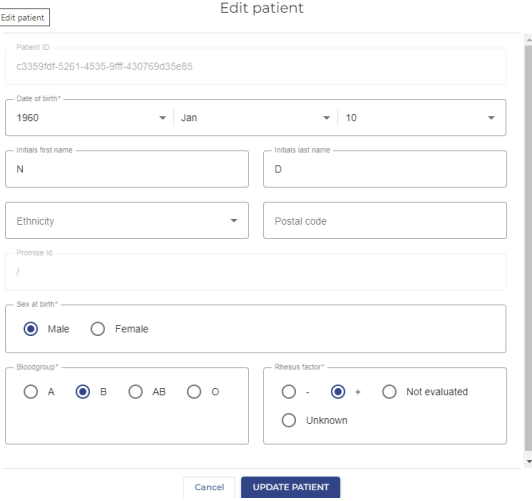
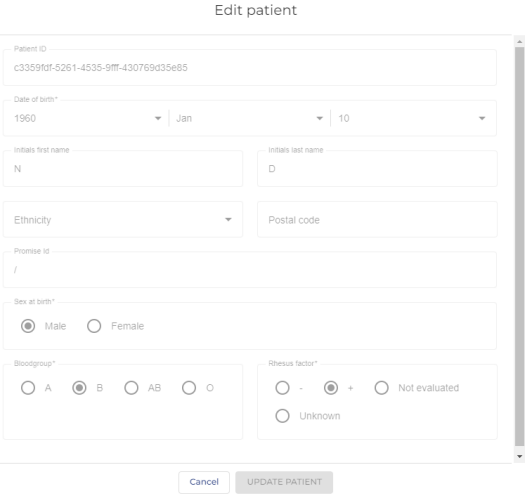
Step	User actions	EBMT Registry
1	<p>Click <i>Edit patient details</i> in the <i>Patient menu</i>.</p> <p>Or</p> <p>Click <i>Edit donor details</i> in the <i>Donor menu</i>.</p>	<p>The <i>Edit patient</i> window opens.</p> <p>Or</p> <p>The <i>Edit donor</i> window opens.</p> <p>For Data editors all editable fields are highlighted.</p> <p>For Data viewers the fields are visible but greyed out to emphasise that they are not editable and disabled.</p>
		
<p>The <i>Edit patient</i> window contains:</p> <ul style="list-style-type: none"> <li>● EBMT patient ID;</li> <li>● information from the Patient registration Data Collection Form;</li> <li>● ProMISe ID for patients registered via the previously used system;</li> <li>● <b>Cancel</b> button - to close the window and discard changes;</li> <li>● <b>Update patient</b> button - to save any introduced changes to Patient details.</li> </ul>	<p>The <i>Edit donor</i> window contains:</p> <ul style="list-style-type: none"> <li>● EBMT donor ID;</li> <li>● information from the Donor registration Data Collection Form;</li> <li>● ProMISe ID for donors registered via the previously used system;</li> <li>● <b>Cancel</b> button - to close the window and discard changes;</li> <li>● <b>Update donor</b> button - to save any introduced changes to Donor details.</li> </ul>	

Table 24, viewing and editing patient/donor details

### View Patient/Donor Consent

Please follow the following step-by-step in order to access and view Patient or Donor informed consent-related data fields from the Patient registration DCF or Donor registration DCF:

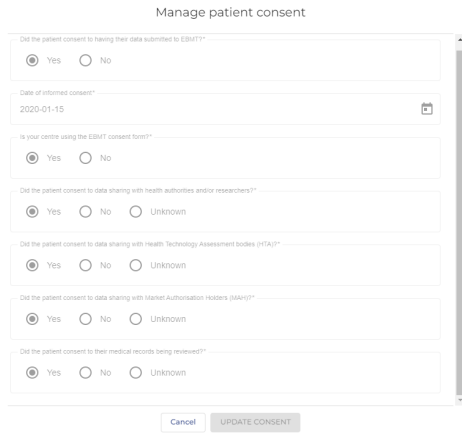
Step	User actions	EBMT Registry
1	Click <i>Manage consent</i> in the <i>Patient menu</i> or in <i>Donor menu</i> .	The <i>Manage Patient Consent</i> or <i>Manage Donor Consent</i> window opens. The fields are visible but greyed out to highlight that they are not editable and disabled. For changing consent information, contact the helpdesk.
		
<p>The <i>Manage patient consent</i> window contains:</p> <ul style="list-style-type: none"> <li>● Patient answers to the consent questions;</li> <li>● <b>Cancel</b> button - to close the window and discard changes;</li> </ul>		<p>The <i>Manage donor consent</i> window contains:</p> <ul style="list-style-type: none"> <li>● Donor answers to the consent questions;</li> <li>● <b>Cancel</b> button - to close the window and discard changes;</li> </ul>

Table 25, viewing patient and donor consent in the EBMT Registry

### View Patient Studies

The following steps can be used to manage patient studies. This concerns both external and EBMT working party studies.

Step	User actions →	EBMT Registry
1	Click <i>Manage studies</i> in the <i>Patient menu</i> .	The <i>Manage Patient Studies</i> window opens.
<div style="text-align: center;"> <p>Manage patient studies</p> <hr/> <p>Participation in study or trial?</p> <p><input type="radio"/> Yes <input checked="" type="radio"/> No</p> <div style="border: 1px solid #ccc; padding: 5px; width: fit-content; margin: 5px auto;">Study name</div> <p>Patient can be included in EBMT studies?</p> <p><input type="radio"/> Yes <input checked="" type="radio"/> No</p> <p>+ ADD EBMT STUDY</p> <hr/> <div style="display: flex; justify-content: center; gap: 20px;"> <span>Cancel</span> <span style="background-color: #0056b3; color: white; padding: 5px 15px; border-radius: 3px;">UPDATE STUDIES</span> </div> </div>		
	<p>The <i>Manage patient studies</i> window contains:</p> <ul style="list-style-type: none"> <li>Information on any non-EBMT studies of the Patient as indicated in the Patient registration form;</li> <li>Statement if the Patient can or cannot be included in EBMT studies;</li> <li><i>+ADD EBMT STUDY</i> button - to add information about EBMT Study once the patient is enrolled. This button is disabled for data viewers.</li> <li><b>Cancel</b> button - to close the window and discard changes;</li> <li><b>Update studies</b> button - to save any introduced changes to Patient studies questions. This button is disabled for data viewers.</li> </ul>	

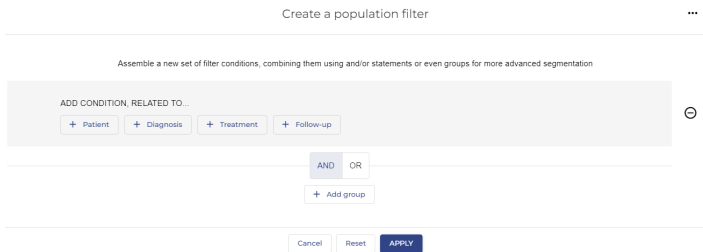
Table 26, viewing patient studies


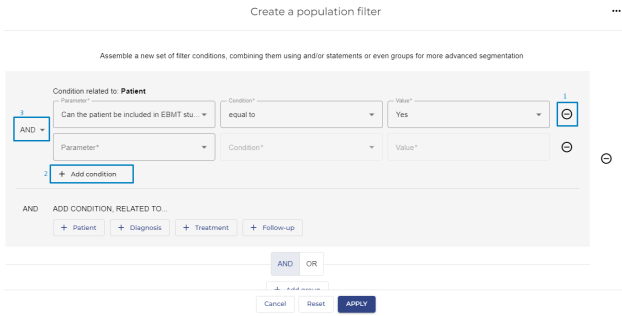
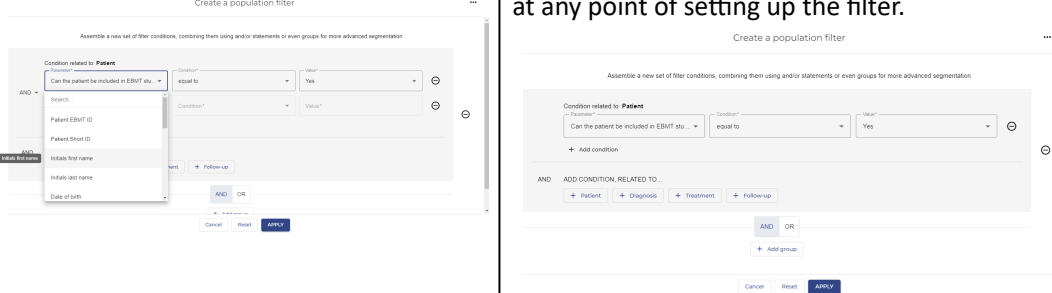
## Set up personal filter

Creating or setting up a personal [filter](#) to filter or search for Patients or Donors follows the below logic:

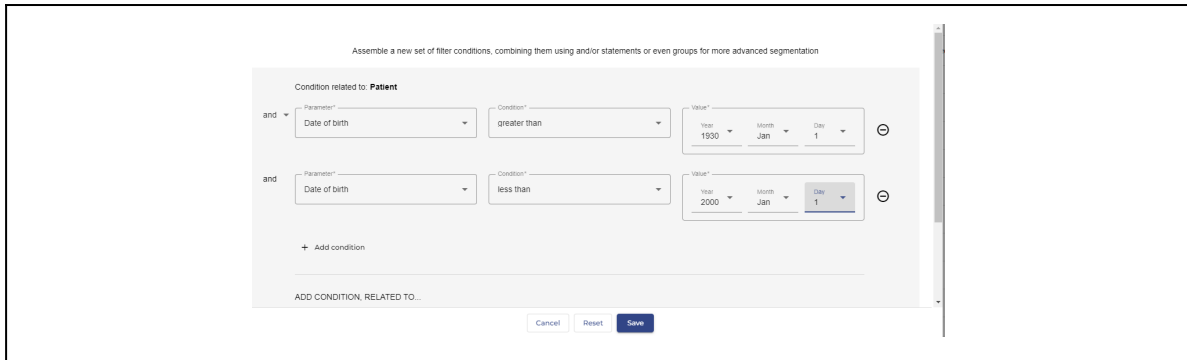
1. Identify all the data fields that will be [Parameters](#) for the User’s personal filter.
  - a. For each data field, identify the event (Data collection form) that contains this data field.
  - b. For each Patient event, identify the event category (if it refers to Patient Diagnosis, Treatment, Follow-up or Other category). There are no event categories for Donors and this step can be skipped.
  - c. For each Event, if there are multiple event types (e.g. Patient underwent multiple auto HCT treatments), will the filter consider all events or only a specific event? If only a specific event is to be considered for this filter, specify if it is the first or the last event from the respective patient timeline.
2. Identify the [Condition](#) and reference [Value](#) for each Parameter (data field). Parameter +Condition + Value will detail filter [Criteria](#).
3. The relationships between the filter criteria can be either:
  - a. *and*: e.g. Criteria A and Criteria B and Criteria C;
  - b. *or*: e.g. Criteria A or Criteria B or Criteria C.
4. The filter Criteria can be divided into separate groups:
  - a. *and*: e.g. (Criteria A and Criteria B) and (Criteria C or Criteria D or Criteria E);
  - b. *or*: e.g. (Criteria A, Criteria B and Criteria C) or (Criteria A, Criteria D and Criteria E).

The process below explains how to set up a personal filter manually from scratch and filter the Patients list. For Donor outcome registry follow the same logic choosing Donor-related filter conditions.

Step	User actions	EBMT Registry
1	From the Patient registry overview page click <i>New filter</i> .	The <i>Create a population filter</i> window opens.
		

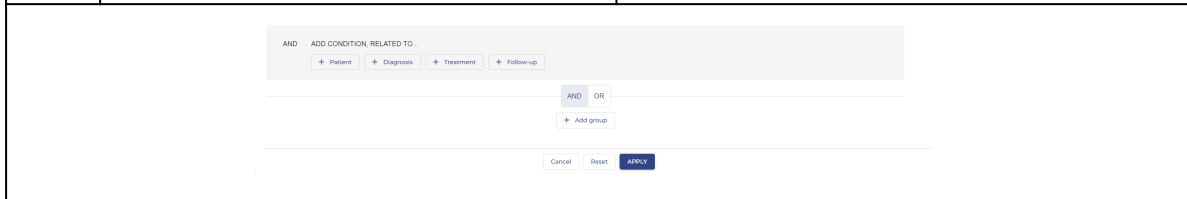
<p>2a</p>	<p>Click <b>+ Patient</b> under <i>Add condition, related to...</i> to specify that data field of interest (filter parameter) that refers to Patient Registration information.</p> <p>If the data field refers to another event category (not to Patient Registration but to Treatment, Diagnosis, Follow-up), choose the correct one by clicking <b>+ [Name of Event Category]</b> button and follow the same logic.</p>	<p>The filter Criteria 1 is shown (Parameter, Condition, Value are 3 dropdown fields) to specify criteria that refer to the Patient Registration form.</p> <ol style="list-style-type: none"> <li>1. The minus icon  is shown to the right from the filter criteria. It can be used to delete/remove this whole filter criteria regardless of whether it is empty or filled in with data.</li> <li>2. <b>+Add condition</b> button is shown under filter criteria and can be used to add one more filter criteria that refers to Patient Registration</li> <li>3. Use <i>and/or</i> toggle button to the left from filter Criteria 1 to specify the relationship between this condition and the following ones. This toggle is shown when 2 or more criteria are shown.</li> </ol>
		
<p>3a</p>	<p>Specify filter Criteria 1 using the dropdowns with answer options (Parameter, Condition, Value).</p>	<p>Selected Parameter, Condition and Value are displayed in filter Criteria 1. These fields remain active and can be amended at any point of setting up the filter.</p>
		
<p>4a</p>	<p>Click <b>+Add condition</b> under displayed filter Criteria if you need to add one more filter Criteria that refers to the Patient Registration form.</p>	<p>Filter Criteria 2 (Parameter, Condition, Value are 3 dropdown fields) to specify criteria that refers to the Patient Registration form is shown.</p>





Specify filter Criteria 2 using the dropdowns with answer options (Parameter, Condition, Value). Selected Parameter, Condition and Value are displayed in filter Criteria 2. These fields remain active and can be amended at any point of setting up the filter.

2b Click the + **[Name of Event Category]** under *Add condition, related to..* to specify to which event category the Event with a data field of the interest (filter parameter) belongs. Event Categories are shown as buttons with the plus sign before the name. The list of events in the chosen Event category is shown. The Event category name is clickable and can be used to go 1 Step back.



3b Click + **[Name of Event]** under *Condition related to [Name of the event category]* to specify what event contains the data field of interest (filter parameter). Events are shown as buttons with plus sign before the name. Filter Criteria 3 is shown (Parameter, Condition, Value are 3 dropdown fields) to specify the criteria that refers to the chosen Event. An additional line under *Condition related to: [Name of Event]* is displayed with a field that describes the Event type. Answer **Any** is chosen by default, use the dropdown to select from the answer options: Any, First, Last, if needed to specify that the Criteria refer only to one particular event from the Patient timeline.

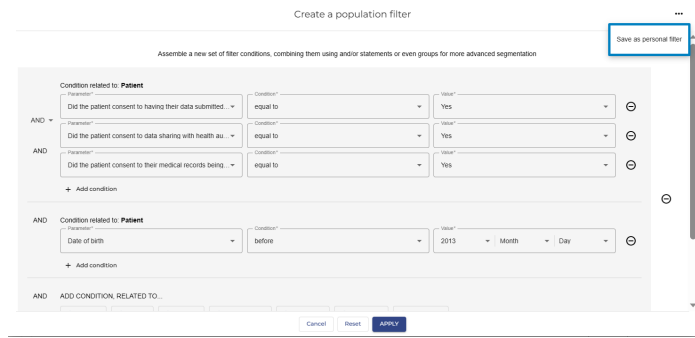
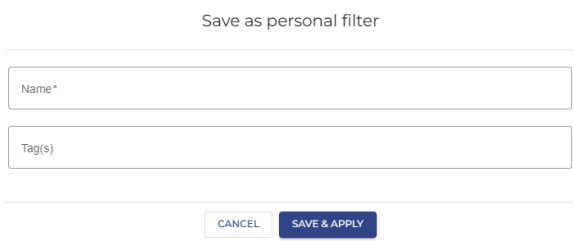


4b	Specify filter Criteria 3 using the dropdowns with answer options (Parameter, Condition, Value).	Selected Parameter, Condition and Value are displayed in filter Criteria 3. These fields remain active and can be amended at any point of setting up the filter.
	Follow the <b>Steps 3a - 4a</b> to add and specify more condition(s) that refer to the chosen Event, if needed.	
	Follow the <b>Steps 2b-4b</b> to add and specify more conditions that refer to any <i>other Event</i> , if needed.	
5	Click the <b>+Add group</b> button at the bottom of the window to add one more group of conditions, if needed.	The new Group of conditions for set-up is shown.  1. Use the <b>AND/OR</b> toggle button shown before the group of conditions 2 to specify the relationship between these groups.
	For the New group of Conditions, follow <b>Steps 2a-4a or 2b-4b</b> to add and specify conditions that refer to the Patient registration form or Patient Event.	
6	Click the <i>Apply</i> button to apply the filter.	Patient Registry overview page shows filtered list of Patients.

Table 27, steps for applying a filter to the patient/donor overview

## Save personal filter

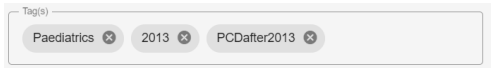
The process below explains how to save an already set up personal filter.

Step	User actions	EBMT Registry
1	<p><a href="#">Set up personal filter</a> that you would like to save.</p>	<p>Click on the three dots icon to call the menu.</p>
		
2	<p>Click <b>Save as personal filter</b> in the appeared menu.</p>	<p><b>Save as personal filter</b> window appears. It contains two fields:  <b>Name</b> - to specify the name of the filter. It will be later shown in the dropdown list of saved personal filters.  <b>Tag(s)</b> - to enter and save some tags, later to find this filter more easily in the list of saved filters.                      It also contains the following buttons:  <b>Cancel</b> button- to cancel the action and close the window.  <b>Save and Apply</b> button - to save the personal filter and apply it to filter the list.</p>
		

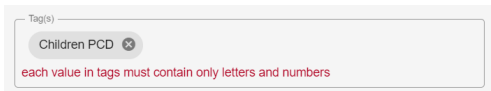
3

Enter the Name you want to assign to this filter into the 1st field Name.

Enter tags into the 2nd field Tag(s): type the tag name and press Enter every time you want to have it entered as a tag.



Tags may include letters and numbers without space. The system will show an error if a space is used while naming a tag. Such tag needs to be removed and entered again in the correct format



Click *Save and Apply* button to save the filter.

*Save as personal filter* window closes. The filter is saved and applied to the overview list. Filtered list is loaded in the main screen.

The filter's name and number of conditions it contains are shown above the filtered list.

The filter is now shown in the list of saved personal filters.

Patient Registry Admin

FILTERS PCDAfter2013 (2 conditions defined) EDIT FILTER EXPORT RESULTS (4) + ADD PATIENT

<input type="checkbox"/>	Short ID	Registration CIC	Registration centre name	UPN	Date of birth	Sex at birth	Date of last event	Last modified	
<input type="checkbox"/>	51021ec	1011	demo centre 1011	1234568	2020-01-02	Female	2023-07-21	2023-07-21	...
<input type="checkbox"/>	93e15bf	12	demo centre 12	12312	2018-02-02	Male	2023-08-01	2023-06-14	...
<input type="checkbox"/>	76812e6	17	demo centre 17	123	2016-02-03	Male	2023-05-10	2023-06-15	...
<input type="checkbox"/>	c95b04	17	demo centre 17	1234	2019-02-03	Male	2023-05-11	2023-06-16	...

4 results Items per page: 20 1 - 4 of 4

Patient Registry Admin

FILTERS + NEW FILTER + ADD PATIENT

Search for personal filters by name or tag

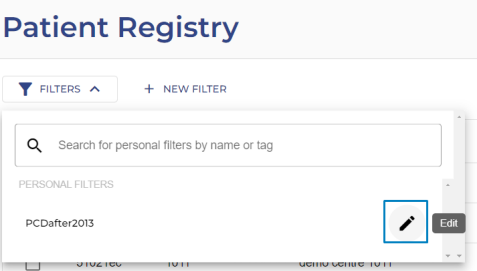
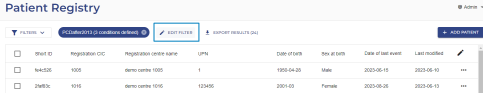
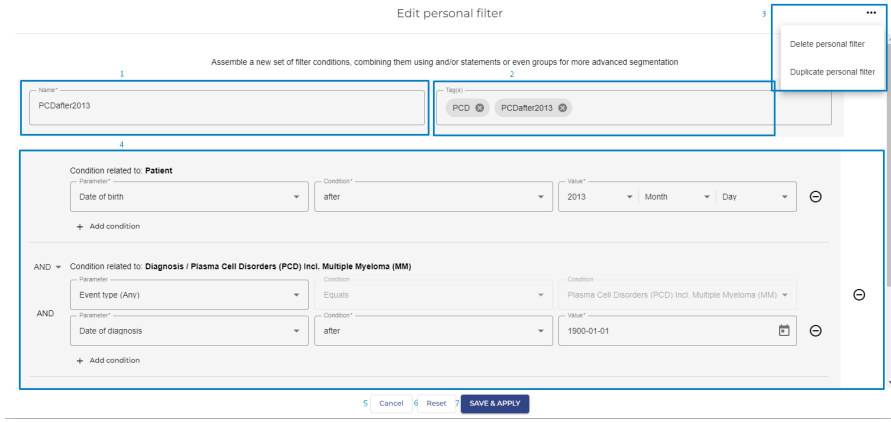
PCDAfter2013

	UPN	Date of birth	Sex at birth	Date of last event	Last modified	
<input type="checkbox"/>	FAKE1	1978-12-10	Female	2023-05-15	2023-07-19	...
<input type="checkbox"/>	007	1960-01-10	Male	2023-07-01	2023-07-08	...
<input type="checkbox"/>	1234568	2020-01-02	Female	2023-07-21	2023-07-21	...
<input type="checkbox"/>	e72aae9	1011	demo centre 1011	789654	2007-10-15	Female / 2023-05-25
<input type="checkbox"/>	1e4c526	1005	demo centre 1005	1	1960-04-28	Male 2023-06-15 2023-06-10
<input type="checkbox"/>	2fa83c	1016	demo centre 1016	123456	2001-03	Female 2023-08-26 2023-06-13
<input type="checkbox"/>	89a004	1003	demo centre 1003	8990	1973-03	Male 2022-02-02 2023-06-12
<input type="checkbox"/>	5693de	616	General Test	006	1984-10-08	Female 2023-01-05 2023-06-22

Table 28, making a personal filter and saving it

## Edit personal filter

The process below explains how to edit an already saved personal filter.

Step	User actions	EBMT Registry
1a	Open the list of saved personal filters and find the filter you would like to edit. Click Edit icon button next to this filter name.  	Edit personal filter window opens.  It contains: <ol style="list-style-type: none"> <li>1. Filter name field</li> <li>2. Filter tag(s) field</li> <li>3. Filter menu</li> <li>4. Filter condition(s)</li> <li>5. <i>Cancel</i> button - to cancel the request and close the window without applying changes.</li> <li>6. <i>Reset</i> button - to reset and empty filter condition(s).</li> <li>7. <i>Save and Apply</i> button - to save any introduced changes into the filter and apply this filter to the overview list.</li> </ol>
1b	When the filter you want to edit is applied to the overview list, click Edit button above the filtered list.  	
		
2	Edit the personal filter as required by introducing changes into available fields.  Click <i>Save and Apply</i> button to save the changes into this personal filter and apply it to filtering the overview list.	<i>Edit personal filter</i> window closes. The filter is saved and applied to the overviewthe list. The filtered list is loaded in the main screen.  The name of the updated filter and number of conditions it contains is shown above filtered list.

Patient Registry Admin

FILTERS PCChaper2013 (3 conditions defined) EDIT FILTER EXPORT RESULTS (24) + ADD PATIENT

<input type="checkbox"/>	Short ID	Registration CIC	Registration centre name	UPN	Date of birth	Sex at birth	Date of last event	Last modified	
<input type="checkbox"/>	1641526	1005	demo centre 1005	1	1990-04-28	Male	2023-06-15	2023-06-10	...
<input type="checkbox"/>	2698736	1016	demo centre 1016	123456	2001-03	Female	2023-06-26	2023-06-13	...
<input type="checkbox"/>	8598504	1003	demo centre 1003	8999	1973-03	Male	2022-02-02	2023-06-12	...
<input type="checkbox"/>	560999e	616	General Test	006	1984-10-08	Female	2023-01-05	2023-06-22	...
<input type="checkbox"/>	04466e5	1003	demo centre 1003	73-99	1980-01-02	Male	2020-02-02	2023-06-29	...

Table 29, editing a personal filter

## Delete personal filter

**Note:** deletion of a personal filter is an irreversible action. It is not possible to restore deleted filters.

The process below explains how to delete any saved personal filter.


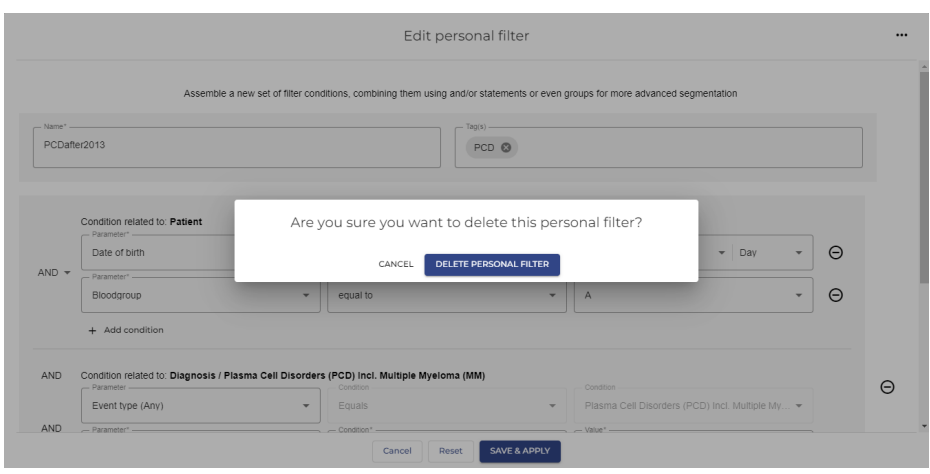
Step	User actions	EBMT Registry
1a	<p>Open the Edit personal filter window as explained <a href="#">here</a>. Click Filter menu icon and then Delete personal filter option.</p> 	<p>The warning window will appear, asking for confirmation on the requested action. It contains: <i>Cancel</i> button - to cancel the request and return to Edit personal filter window. <i>Delete personal filter</i> button - to confirm the deletion of this personal filter.</p>
		
2	<p>Click the <i>Delete personal filter</i> button to confirm the deletion.</p>	<p>This personal filter is deleted from the system and thus removed from the list of saved personal filters. The unfiltered overview list is loaded in the main screen</p>

Table 30, deleting a personal filter

## Duplicate personal filter

The process below explains how to duplicate or create a copy of any saved personal filter.

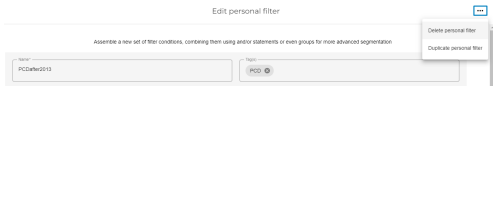
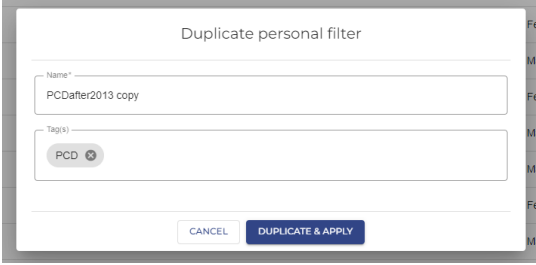
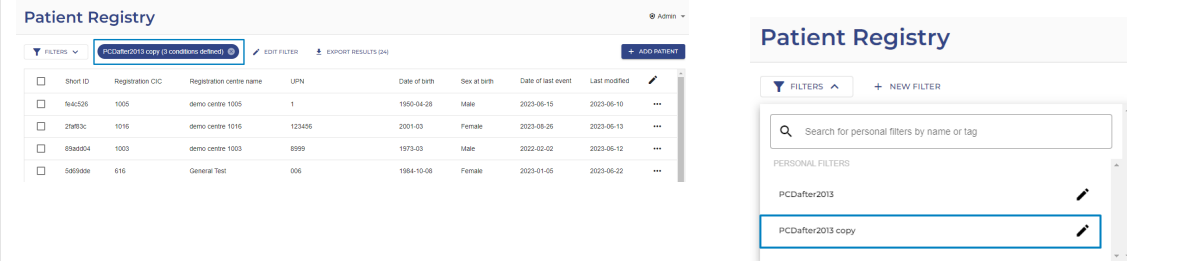
Step	User actions	EBMT Registry
1	<p>Open the Edit personal filter window as explained <a href="#">here</a>. Click <i>Filter menu icon</i> and then <i>Duplicate personal filter</i> option.</p> 	<p>The <i>Duplicate personal filter</i> window will appear. It contains: <i>Name</i> field - to enter the name of the duplicate filter. By default, this field contains the name of the original filter followed by the word copy. <i>Tags</i> field - to enter the tags for the duplicate filter. By default, this field contains the tags of the original filter. <i>Cancel</i> button - to cancel the request and return to <i>Edit personal filter</i> window. <i>Duplicate personal filter</i> button - to confirm saving the duplicate of this personal filter with entered into the <i>Duplicate personal filter</i> window name and tags.</p>
		
2	<p>Edit the <i>Name</i> and <i>Tag(s)</i> fields of the <i>Duplicate personal filter</i> window as required.  Click <i>Duplicate personal filter</i> button to confirm the action.</p>	<p>The duplicate filter is saved and applied to the overview list. The filtered list is loaded on the main screen.  The name of the filter and number of conditions it contains is shown above the filtered list.  The filter is now shown in the list of saved personal filters.</p>
		

Table 31, duplicating a personal filter



## View anonymous events

The process below explains how to access and view [anonymous events](#) in the user [Context](#).

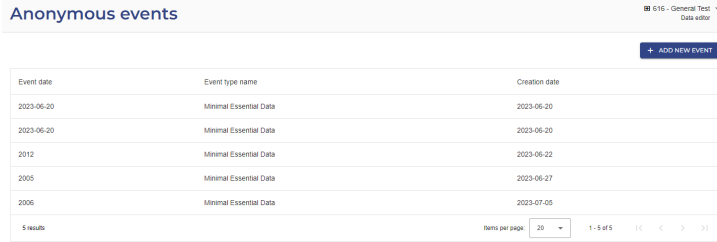
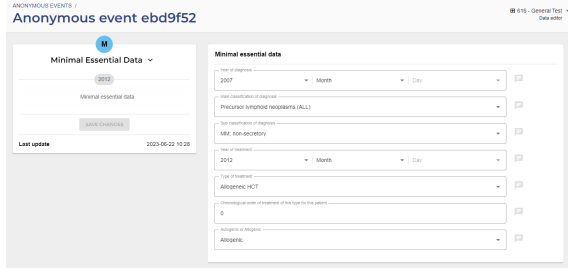
Step	User actions	EBMT Registry
1	Click <i>Anonymous events</i> in the <a href="#">Navigation menu</a> .	Anonymous events overview page opens
		
2	Click the event you wish to open and view.	The Anonymous event is loaded and shown on the main screen.
		

Table 32, viewing anonymous events

## Print Patient or Donor Event

Since the EBMT Registry is a web application, users are always able to print the webpage through the web browser, but they are advised to use the Printing functionality available in the EBMT Registry, as the produced for printing document is more optimised.

Remember that printing document contains sensitive patient or donor data and all security measures should be applied

Step	User actions	EBMT Registry
1	Open the Patient event that you wish to print. Click on <i>Print</i> in the Event form summary.	The confirmation warning appears. It contains the following buttons: <i>Cancel</i> - to cancel the printing request and return to the patient event form. <i>I understand</i> - to confirm the user agrees and understand the shown warning and agrees to comply with the mentioned statement.
<p>Sensitive patient data</p> <hr/> <p>All users of the EBMT Registry must comply with the EBMT Registry Conditions of Use, Data Protections laws in existence in each individual country, and the General Data Protection Regulations (GDPR 2016/679). By proceeding with this export, I understand that I am downloading sensitive patient- and/or donor-related data from the EBMT Registry and I agree to comply with the requirements mentioned above.</p> <hr/> <p>CANCEL    <b>I UNDERSTAND</b></p>		
2	Read carefully the warning and click <i>I understand</i> to confirm and proceed to printing. Or click Cancel to cancel the printing.	The event form is transformed into a file in pdf format and downloaded to the users computer. (into Downloads folder) ready to be printed.

Table 33, printing patient or donor events

The printed version of an event received as a result of the currently explained process is not identical to the paper version of a Data Collection Form because it does not show answer options to data fields, does not display questions dependent on other factors than entered values, etc.

## Exporting data

Please make sure you read all the information on [Exports](#) provided in the previous chapters. Please pay special attention to the [Export security](#).

The content of the exported file is detailed in the [Export content](#) section.

### Remember:

- No exports can be created between 02:00 and 07:00 AM CET. This is when the synchronisation between the application and analytical database happens.
- Export may include maximum 250.000 patients. Please contact the Helpdesk if you require larger scope of exported data.

### Export full context

The process below explains how to export all the data of all patients in the user current context. If a user has access to multiple contexts, the export shall be done separately in each of these contexts.

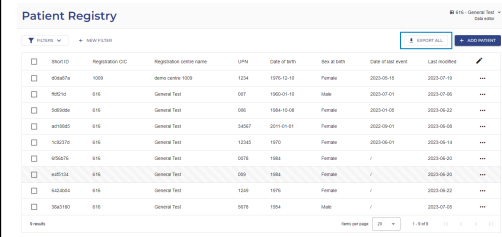
Step	User actions	EBMT Registry
1	<p>In the Patient overview page click the <i>Export all</i> button.</p> 	<p><i>Request export</i> window appears. It includes:</p> <ul style="list-style-type: none"> <li><i>Name</i> field - to enter the name of the export file. By default this field contains the name with the date and scope.</li> <li>File type options (radio buttons)</li> <li><i>Cancel</i> button - to cancel the export request and return to the overview page.</li> <li><i>Export</i> button - to confirm the action and request export file generation.</li> </ul>
2	<p>Edit the name of the export file you wish to generate.</p> <p>Select the file type from the list offered formats.</p> <p>Click <i>Export</i> to proceed with export file generation.</p>	<p><i>Request export</i> window disappears. The overview page is shown on the user screen</p> <p>The Export request with the current status can be checked in the <a href="#">Exports tab</a> of the Navigation menu.</p>

Table 34, exporting full context

## Export filtered results

The process below explains how to export all the data of a filtered list of patients.

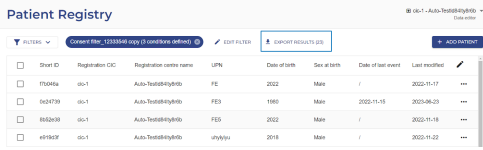
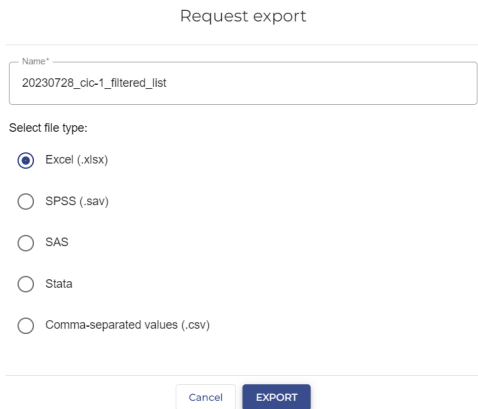
Step	User actions →	EBMT Registry
1	<p>In the Patient overview page with applied filter click the <i>Export results</i> button.</p> 	<p><i>Request export</i> window appears. It includes:</p> <ul style="list-style-type: none"> <li><i>Name</i> field - to enter the name of the export file. By default this field contains the name with the date and scope.</li> <li>File type options (radio buttons)</li> <li><i>Cancel</i> button - to cancel the export request and return to the overview page.</li> <li><i>Export</i> button - to confirm the action and request export file generation.</li> </ul>
		
2	<p>Edit the name of the export file you wish to generate.</p> <p>Select the file type from the list offered formats.</p> <p>Click <i>Export</i> to proceed with export file generation.</p>	<p><i>Request export</i> window disappears. The overview page is shown on the user screen</p> <p>The Export request with the current status can be checked in the <a href="#">Exports tab</a> of the Navigation menu.</p>

Table 35, exporting all the data of a filtered list of patients

## Export selected list

The process below explains how to export all data of selected list of patients.

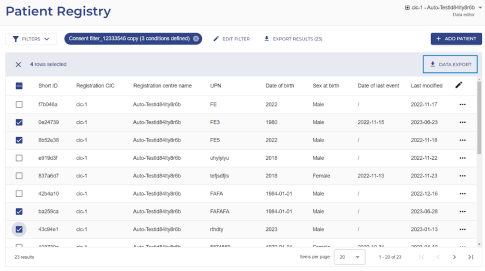
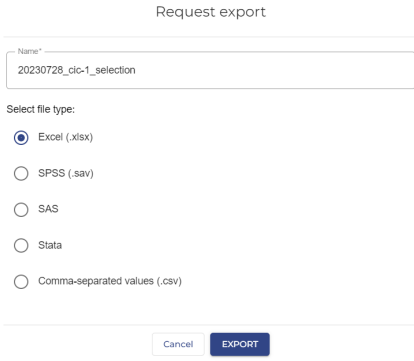
Step	User actions	EBMT Registry
1	<p>In the Patient overview page with applied filter or without any applied filter select the patients you want to include to the export file.</p> <p>click the <i>Data export</i> button.</p> 	<p><i>Request export</i> window appears.</p> <p>It includes:</p> <p><i>Name</i> field - to enter the name of the export file. By default this field contains the name with the date and scope.</p> <p>File type options (radio buttons)</p> <p><i>Cancel</i> button - to cancel the export request and return to the overview page with selection.</p> <p><i>Export</i> button - to confirm the action and request export file generation.</p>
		
2	<p>Edit the name of the export file you wish to generate.</p> <p>Select the file type from the list offered formats.</p> <p>Click <i>Export</i> to proceed with export file generation.</p>	<p><i>Request export</i> window disappears. The overview page is shown on the user screen with previously done selection.</p> <p>The Export request with the current status can be checked in the Exports tab of the Navigation menu.</p>

Table 36, exporting all the data of selected list of patients

## Data Editor-related functionality

The EBMT Registry was designed so that users can fill a paper Data Collection Form first and then enter the information into the EBMT Registry, or fill the information online directly. The use of the EBMT Registry online platform is preferred, as it saves time, avoiding mistakes while transferring data from paper to the EBMT Registry, the system will also check for potential errors (validation checks) and navigate the user through the required fields (depending on answer to a question, dependant sub questions appear).

Reminder: It is important to save changes regularly during the data entry process.

### Add Patient

The process below explains how to register (add) a new patient to the EBMT Registry.

Step	User actions	EBMT Registry
1	From the Patient Registry overview page click <i>Add patient</i> .	<p><i>Add a new patient</i> window opens. It contains data fields from the a Patient registration form and is represented as 3 steps form (it can be considerate as 3 pages or sections of the same form):</p> <ol style="list-style-type: none"> <li>1. <b>Patient consent</b> - contains data fields related to the Patient Informed consent.</li> <li>2. <b>Patient registration</b> - includes data fields related to the general patient registration data (UPN, birthdate, initials, etc.).</li> <li>3. <b>Patient studies</b> - data fields to inform if a patient is part of any non-EBMT study and study-related data.</li> </ol> <p>At the bottom of the form there are shown the following buttons:</p> <p><b>Cancel</b> - use this button to cancel new Patient creation. The Add a new patient window will be closed, already entered information, if any, will be lost.</p> <p><b>Next</b> - use this button to proceed to the next step (page) of the registration form.</p>

2

Answer questions in the Patient consent section. Remember to add the Date of the Patient informed consent. Click the *Next* button at the bottom of the *Add a new patient* window.

It is important that all questions of this section are mandatory and shall not be left blank. If a user proceed to next sections of the *Add a new patient*, the title of the Patient consent section will be marked with an Error and shown as following




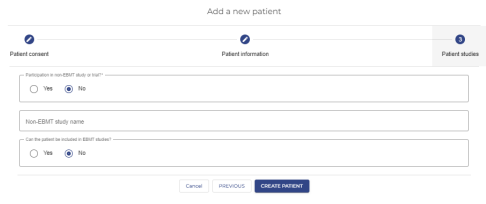
Date of informed consent form remains not editable. Please request the change of ICF date through the Helpdesk if needed.

The Patient registration section will be shown in the *Add a new patient* window.

At the bottom of the form there are shown the following buttons:  
**Cancel** (explained in the Step 1).  
**Previous** - use this button to go back to the previous section Patient consent (Step 1).  
**Next** (explained in Step 1).

Data editors in VR context that *Add a new patient* will see one extra data field **Centre**, where they must specify the registration centre for this Patient.

<p>3</p>	<p>Answer questions in the Patient registration section.</p> <p>Click the <i>Next</i> button at the bottom of the <i>Add a new patient</i> window.</p> <p>UPN number is a critical data field that should be entered correctly at this step. Please check it is correct before proceeding.</p> <p>All data fields (except Ethnicity and Postal code) are shown as mandatory and shall be filled in. If a user proceed to the next section of the <i>Add a new patient</i> or returns to a previous one, the title of the Patient registration section will be marked with an Error and shown as following:</p>  <p>Patient information Form invalid</p> <p>Due to legal restrictions in some countries, in rare cases patients initials may not be reported, the field will still be highlighted with an error, but it will not block Adding a new Patient to the EBMT Registry.</p>	<p>The Patient Studies section will be shown in the <i>Add a new patient</i> window.</p> <p>At the bottom of the form are the following buttons:</p> <p><b>Cancel</b> (explained in the Step 1).</p> <p><b>Previous</b> - use this button to go back to the previous section, Patient consent (Step 1).</p> <p><b>Create patient</b> - the button to confirm Adding a new patient to the EBMT Registry with registration data entered in the <i>Add a new patient</i> window.</p>
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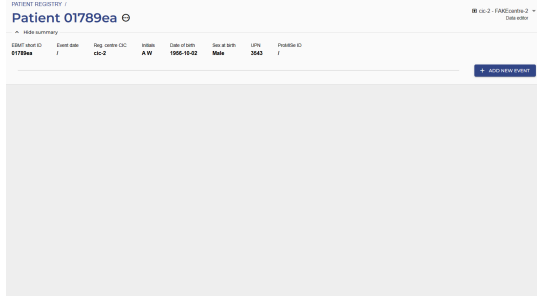
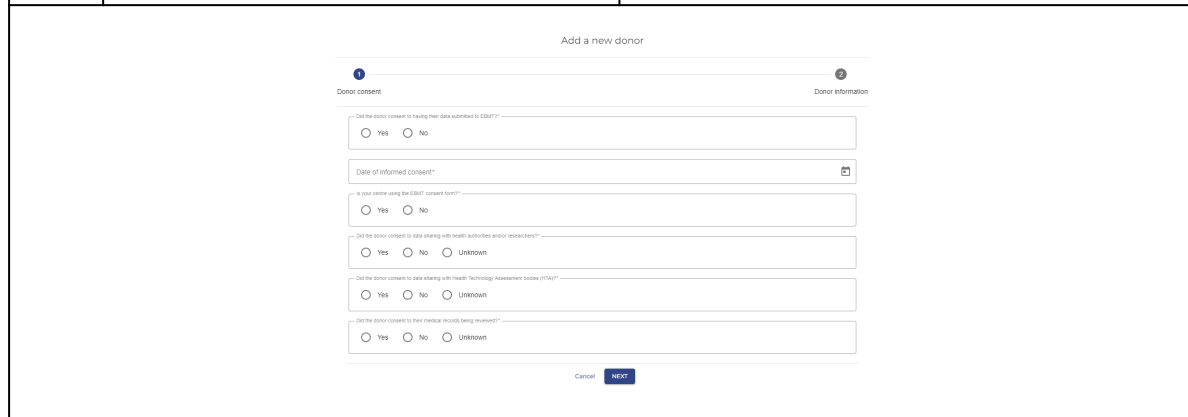
<p>4</p>	<p>Answer questions in the Patient studies section.</p> <p>Click the <i>Create patient</i> button at the bottom of the <i>Add a new patient</i> window.</p>	<p>If all mandatory fields were filled in the <i>Add a new patient</i> window, the patient <a href="#">duplicate check</a> will be performed, and if it is successful, the new Patient is successfully created in the EBMT Registry, and the Patient page is shown on the main screen.</p> <p>If the data of the patient the user is trying to register is matching the data of an existing patient, there will be shown a warning or error message, as explained in detail in the <a href="#">Duplicate check</a> section.</p> <p>If there is missing information in the mandatory fields, the corresponding section of the form is highlighted with an error, the data field is highlighted in red. <i>The Create patient</i> button may be clicked, but the <i>Add a new patient</i> window remains open. Add information to the mandatory fields and click the <i>Create patient</i> button.</p>
		

Table 37, instructions on how to add a patient to the EBMT Registry

## Add Donor

The process below explains how to register (add) a new donor to the EBMT Registry.


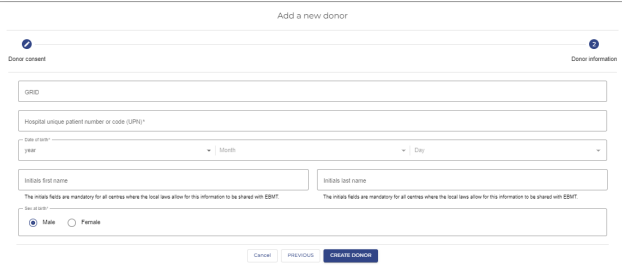

Step	User actions	EBMT Registry
1	From the Donor outcomes registry overview page click <i>Add donor</i> .	<p><i>Add a new donor</i> window opens. It contains data fields from a Donor registration form and is represented in a two steps form (it can be considered as two pages or sections of the same form):</p> <ol style="list-style-type: none"> <li><b>Donor consent</b> - contains data fields related to the DonorInformed consent.</li> <li><b>Donor registration</b> - includes data fields related to the general donor registration data (GRID, Donor ID, birthdate, initials, etc.).</li> </ol> <p>At the bottom of the form, there are shown the following buttons:</p> <p><b>Cancel</b> - use this button to cancel new Donor creation. The Add a new donor window will be closed, and already entered information, if any, will be lost.</p> <p><b>Next</b> - use this button to proceed to the next step (page) of the registration form.</p>



The screenshot shows a web form titled "Add a new donor" with two main sections: "Donor consent" and "Donor information". The "Donor consent" section contains five radio button questions:

- Did the donor consent to having their data submitted to EBMT? (Yes/No)
- Date of informed consent\* (calendar icon)
- Is your center using the EBMT consent tool? (Yes/No)
- Did the donor consent to data sharing with health authorities and/or researchers? (Yes/No/Unknown)
- Did the donor consent to data sharing with Health Technology Assessment bodies (HTA)? (Yes/No/Unknown)
- Did the donor consent to their medical records being reviewed? (Yes/No/Unknown)

At the bottom of the form, there are "Cancel" and "NEXT" buttons.

<p>2</p>	<p>Answer questions in the Donor consent section. Remember to add the Date of the Donor informed consent.</p> <p>Click the <i>Next</i> button at the bottom of the <i>Add a new donor</i> window.</p> <p>It is important that all questions of this section are mandatory and shall not be filled in. If a user proceeds to the next section of the <i>Add a new donor</i>, the title of the Donor consent section will be marked with an Error and shown as follows</p> 	<p>The Donor registration section will be shown in the <i>Add a new donor</i> window.</p> <p>At the bottom of the form there are shown the following buttons:</p> <p><b>Cancel</b> (explained in the Step 1).</p> <p><b>Previous</b> - use this button to return to the previous section Donor consent (Step 1).</p> <p><b>Create donor</b> - the button to confirm Adding a new donor to the EBMT Registry with registration data entered in the <i>Add a new donor</i> window.</p> <p>Data editors in VR context that Add a new donor will see one extra data field <b>Centre</b>, where they must specify the registration centre for this Donor.</p>
		
<p>3</p>	<p>Answer questions in the Donor registration section.</p> <p>Click the <i>Create donor</i> button at the bottom of the <i>Add a new donor</i> window.</p> <p>If a user returns to a previous section, the title of the Donor registration section will be marked with an Error and shown as following:</p>  <p>Due to legal restrictions in some countries, in rare cases donor initials may not be reported, the field will still be highlighted with an error, but it will not block Adding a new donor to the EBMT Registry.</p>	<p>If the data is entered correctly, the new Donor is successfully created in the EBMT Registry, and the Donor page is shown in the main screen.</p> <p>If there is missing information in the mandatory fields, the corresponding section of the form is highlighted with an error, the data field is highlighted in red. <i>The Create donor</i> button may be clicked, but the <i>Add a new donor</i> window remains open. Add information to the mandatory fields and click the <i>Create patient</i> button.</p>

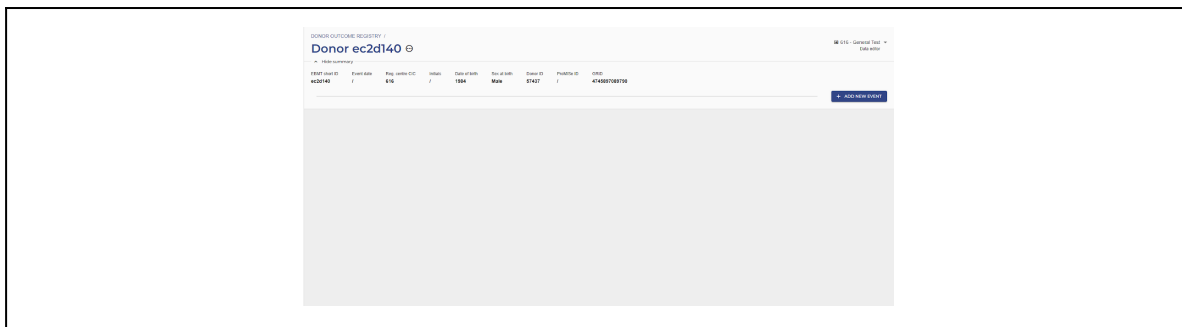
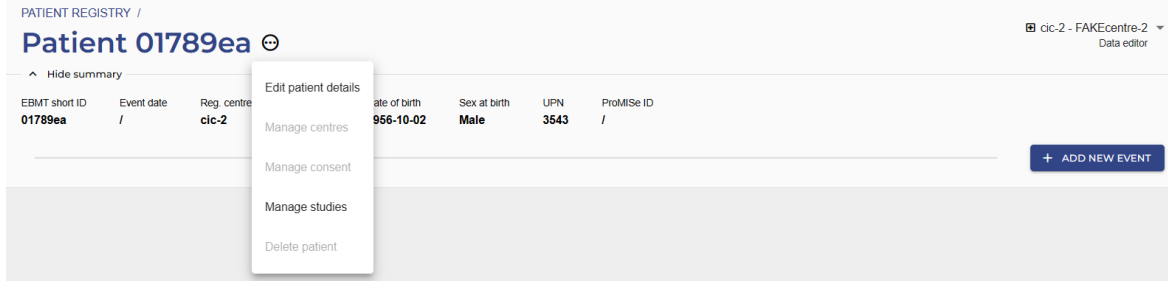


Table 38, instructions on how to add a donor to the EBMT Registry

## Edit Patient details

Please follow the following step-by-step in order to edit Patient general details-related data fields from the Patient registration DCF:

- A. date of birth;
- B. initials for name;
- C. initials for surname;
- D. ethnicity;
- E. postal code;
- F. sex at birth;
- G. blood group;
- H. rhesus factor.

Step	User actions	EBMT Registry
1	In the Patient page click on the three dots button to the right from the Patient short ID to call the Patient menu.	The <b>patient menu</b> will open.
		
2	Click on <b>Edit patient details</b> in the Patient menu.	<p>The <b>Edit patient</b> window will appear.</p> <p>There are the following buttons at the bottom of the window:</p> <p><b>Update patient</b> - to apply the changes in the shown data fields.</p> <p><b>Cancel</b> - to discard the changes. Use this button to close the Update this patient window without saving any changes done.</p>

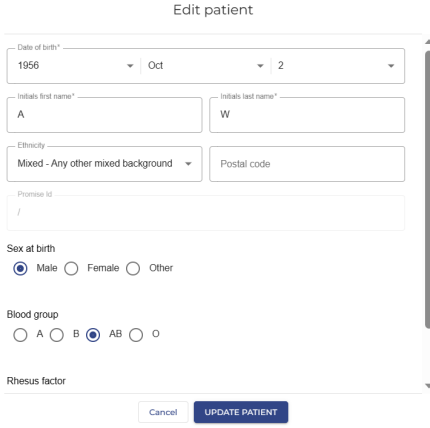
Step	User actions	EBMT Registry
		
5	Edit required fields. Click the <i>Update patient</i> button to apply the changes	The patient details are updated. The <i>Update this patient</i> window disappears. Patient page is displayed at the main screen.

Table 39, instructions on how to update patient information

Note: The Edit patient window also shows the EBMT Patient ID if it is required to see this information through the user interface. This field is not editable but is for information purposes only.

## Edit Donor details

Please follow the following step-by-step to edit Donor general details and related data fields from the Donor registration DCF:

- A. date of birth;
- B. initials for name;
- C. initials for surname;
- D. sex at birth.

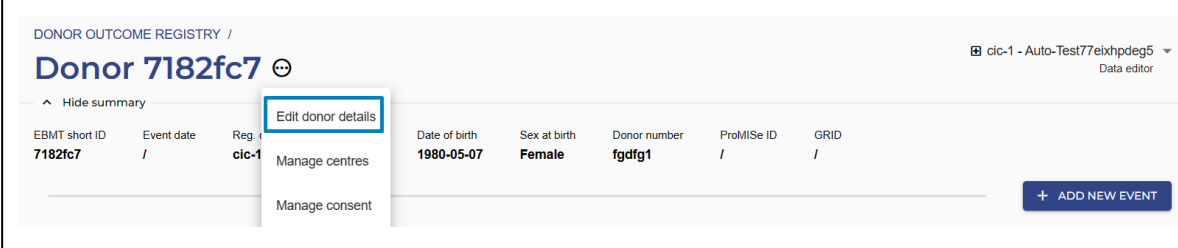
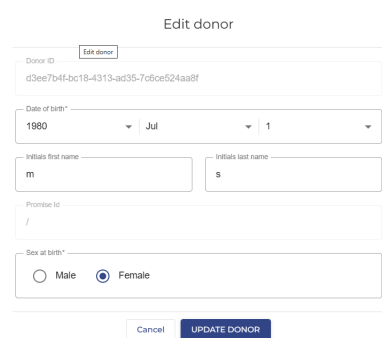
Step	User actions	EBMT Registry
1	In the Patient page click on the three dots button to the right from the Patient short ID to call the Patient menu.	The <b>patient menu</b> will open.
		
2	Click on <b>Edit donor details</b> in the Patient menu.	The <b>Edit donor</b> window will appear. There are the following buttons at the bottom of the window: <b>Update donor</b> - to apply the changes in the shown data fields. <b>Cancel</b> - to discard the changes. Use this button to close the Update donor window without saving any changes done.
		
5	Edit required fields. Click the <b>Update patient</b> button to apply the changes	The patient details are updated. The <b>Update this patient</b> window disappears. Patient page is displayed at the main screen.

Table 40, instructions on how to update donor information

Note: The Edit donor window also shows the EBMT Donor ID if it is required to see this information through the user interface. This field is not editable but for information purposes only.

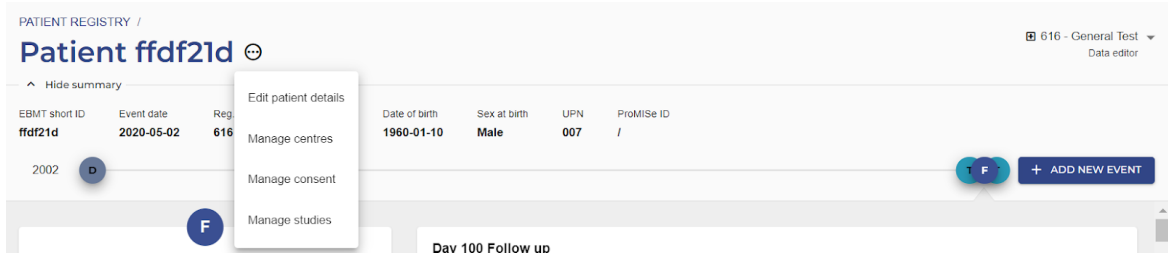
## Edit Patient studies

Follow the instructions below to edit patient data related to non-EBMT studies, in particular:

- a. Edit the information as to whether the patient is participating in any non-EBMT study or trial and if answered Yes, to add study name;
- b. Indicate whether the patient can be included in the EBMT studies.

Information on patient enrolment into EBMT studies is managed by EBMT staff and shall not be added or edited by users from Centres or National registries.

EBMT staff will add every EBMT study-related information (E.g. *Working group; Study name; Study number; Study type; Patient ID number*).

Step	User actions	EBMT Registry
1	In the Patient page click on the three dots button to the right from the Patient short ID to call the Patient menu.	The <b>Patient menu</b> will open.
		
2	Select <b>Manage studies</b> from the patient menu.	The <b>Manage patient studies</b> window will appear. There are the following buttons at the bottom of the window: <b>Update studies</b> - to apply and save the changes in shown data fields. <b>Cancel</b> - to discard the changes. Use this button to close the Manage patient consent window without saving any changes done.



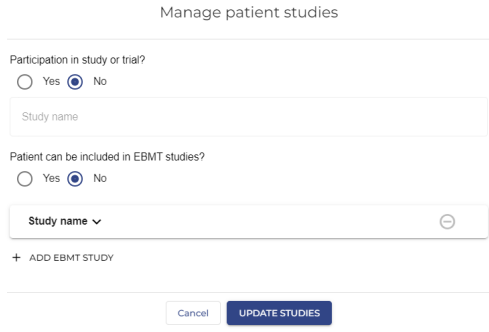
Step	User actions	EBMT Registry
		
5	Edit required fields. Click the <i>Update studies</i> button to apply the changes.	The patient study-related data is updated. The <i>Manage patient studies</i> window disappears. Patient page is displayed on the main screen.

Table 41, instructions on how to update patient studies

## Delete Patient/Donor

Only the Administrator can delete a patient in exceptional circumstances.  
Data viewers and data editors cannot delete any patient or donor.

### Add new event

Follow the instructions below to add a new patient or donor [event](#).

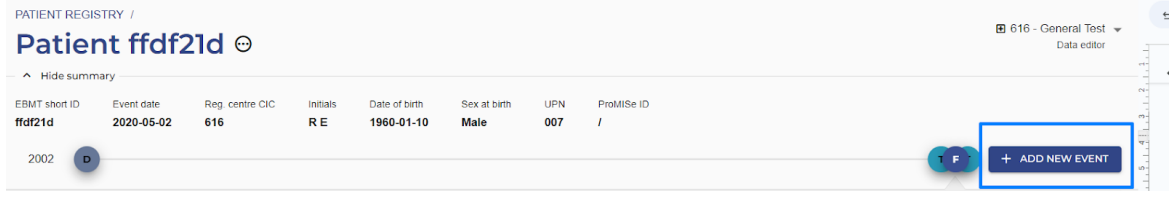
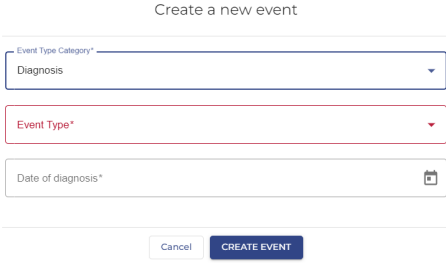
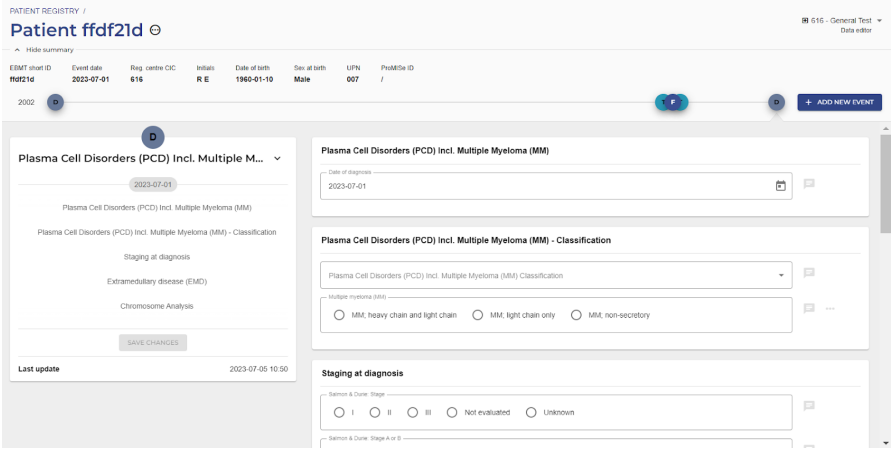
Step	User actions	EBMT Registry
1	In the Patient page (or Donor page) click the <b>Add new event</b> button located on the right from the patient timeline.	The <b>Create a new event</b> window will appear.
		
2	<p>Fill in the <b>Create a new event</b> form, specifying:</p> <ul style="list-style-type: none"> <li>a. Event type category: <i>Diagnosis/Treatment/Follow Up/Other</i>; (this field is not shown for Donor events)</li> <li>b. Event type (name of the data collection form for the event you want to register);</li> <li>c. Event date.</li> </ul>	
4	Once fields are filled in correctly, click the <b>Create event</b> button.	The event is created in the Patient/Donor page, event form is shown in the main screen.
		

Table 42, instructions on how to add an event to a patient or donor timeline

## Edit event

Follow the instructions below to edit any registered patient or donor [event](#).

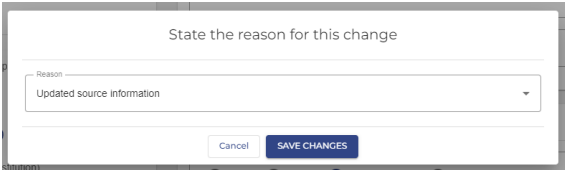

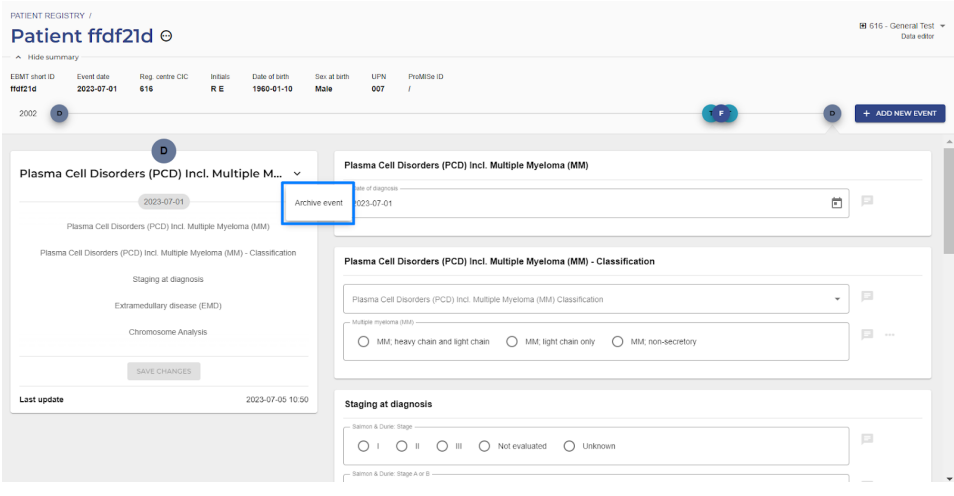
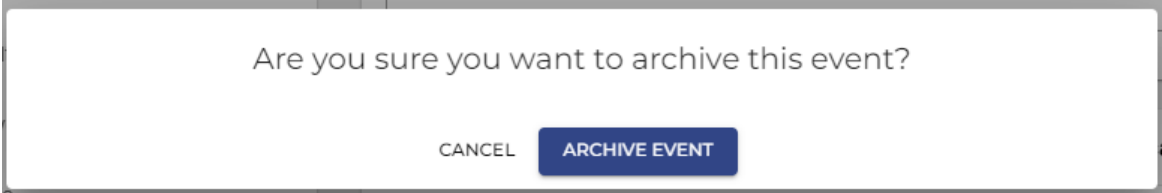
Step	User actions	EBMT Registry
1	<p>In the <i>Patient page (or Donor page)</i> open the event form you wish to edit (add new data or edit data, etc.).</p> <p>Make edits in the required data fields.</p> <p>Click Save changes button in the Event summary.</p>	<p>The warning message asks for confirmation and the reason for this change.</p> <p>It is possible to indicate the following reasons:</p> <ul style="list-style-type: none"> <li>● Updates source information;</li> <li>● Data entry error/mistake.</li> </ul> <p>The window also contains the buttons:</p> <p><i>Cancel</i> - to cancel the request to save introduced changes. Use this button to cancel saving the changes to the database.</p> <p><i>Save changes</i> - use this button to confirm saving changes to EBMT Registry database.</p>
		
2	<p>Indicate the reason for introduced changes from the dropdown list and click <i>Save changes</i> button</p>	<p>The changes are saved to the EBMT Registry database. The new version of the event form is created and recorded in the Audit log.</p> <p>The event form with introduced changes is displayed in the main screen.</p>

Table 43, instructions on editing an event on the patient or donor timeline

## Delete event

Follow the instructions below to remove the patient’s or donor’s [event](#) from the timeline.

The event is not deleted from the system in full. Data from the event is removed from the database, but it remains in the [Audit trail](#), which is why in the user interface, this action is called Archive event.

Step	User actions	EBMT Registry
<p><b>1</b></p>	<p>In the <i>Patient page (or Donor page)</i> open the event you wish to delete.</p> <p>Click the icon  to the right from the event form name to call the event menu.</p>	<p>The event menu will appear.</p>
		
<p><b>2</b></p>	<p>Click Archive event. The warning message asking to confirm the action will be shown. It includes the following buttons:</p> <p><i>Archive event</i> button - to remove the event from the Patient/Donor page and event data from the database.</p> <p><i>Cancel</i> - to cancel this request and leave the event in the Patient/Donor page and event data in the database.</p>	

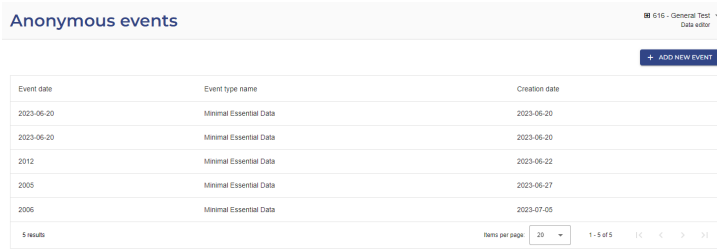
Step	User actions	EBMT Registry
4	Click <i>Archive event</i> button.	The event disappears from the Patient/Donor timeline. The event with the latest date is loaded and shown on the main screen.

Table 44, instructions on how to delete (archive) an event

## Add anonymous event

Please note that the process below may slightly change for optimisation purposes or due to changes in the configuration of the form to register treatment for non-consenting patients.

The process below explains how to add an [anonymous event](#) to register minimum essential data on treatment of non-consenting patients in the user [Context](#).

Step	User actions	EBMT Registry
1	Click <i>Anonymous events</i> in the <a href="#">Navigation menu</a> .	Anonymous events overview page opens.
		
2	Click <i>Add new event</i> button.	<p>The <i>Create a new event</i> window will appear. It contains:</p> <ul style="list-style-type: none"> <li>Date entered - to create the anonymous event, enter the date you are reporting the anonymous event</li> <li>Date field - to enter the year (date) of the treatment</li> <li>Cancel button - to cancel anonymous event creation and go back to Anonymous events overview page.</li> <li>Create event button - to create an anonymous event in the system</li> </ul>

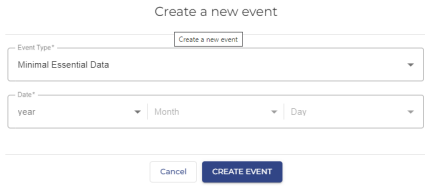
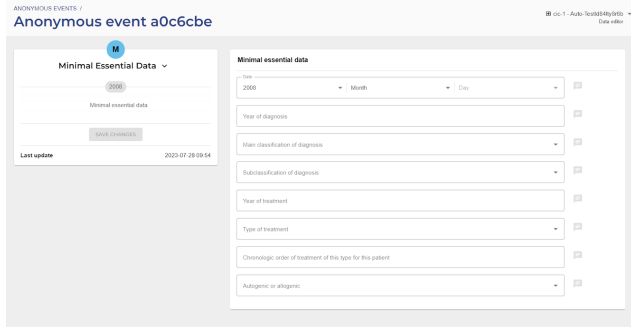
		
3	<p>Fill in the date of the anonymous event and click the <i>Create event</i> button.</p>	<p>New anonymous event with a unique number is created in the system and is loaded on the screen.</p>
		
	<p>Fill-in the data in the data fields and click the <i>Save changes</i> button.</p>	<p>The data is saved for these anonymous events in the database.</p>

Table 45, instructions on how to add anonymous events

### Edit anonymous event

Follow the instructions below to edit any registered [anonymous event](#).

Note that the events are made non-identifiable on purpose, so carefully check the entered information before editing data.

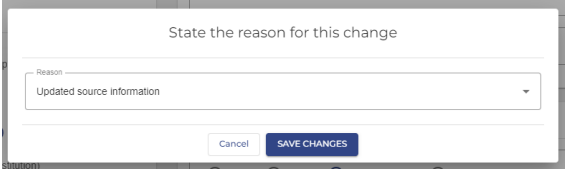
Step	User actions	EBMT Registry
1	<p>In the Anonymous events overview page, open the event form you wish to edit (add new data or edit data, etc.).</p> <p>Make edits in the required data fields.</p> <p>Click Save changes button in the Event summary.</p>	<p>The warning message asks for confirmation and to state the reason for this change.</p> <p>It is possible to indicate the following reasons:</p> <ul style="list-style-type: none"> <li>● Updates source information;</li> <li>● Data entry error/mistake.</li> </ul> <p>The window also contains the buttons: <i>Cancel</i> buttons to cancel the request to save introduced changes. Use this button to cancel saving the changes to the database.</p> <p><i>Save changes</i> - use this button to confirm saving changes to EBMT Registry database.</p>
		
2	<p>Indicate the reason for introduced changes from the dropdown list and click <i>Save changes</i> button</p>	<p>The changes are saved to the EBMT Registry database. The new version of the event form is created and recorded in the Audit log.</p> <p>The anonymous event form with introduced changes is displayed on the main screen.</p>

Table 46, instructions on how to edit an anonymous event



### Delete anonymous event

Follow the instructions below to remove any anonymous event from the system.

Note that the events are made non-identifiable on purpose, so carefully check the entered information before editing data.

The anonymous event is not deleted from the system in full. Data from the event is removed from the database, but it remains in the [Audit trail](#), which is why, in the user interface, this action is called Archive event.


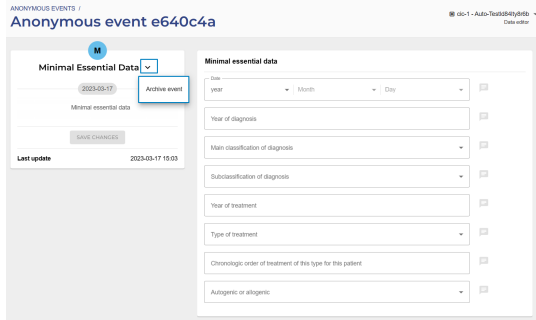
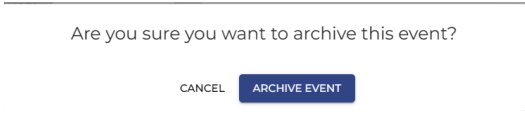
Step	User actions	EBMT Registry
1	<p>Open the page of the Anonymous event page you wish to delete.</p> <p>Click the icon  to the right from the event form name to call the event menu.</p>	<p>The event menu will appear.</p>
		
2	<p>Click Archive event.</p>	<p>The warning message asking to confirm the action will be shown.</p> <p>It includes the following buttons:  <i>Archive event</i> button - to remove the Anonymous event from the system.  <i>Cancel</i> - to cancel this request and leave the event in the database.</p>
		
3	<p>Click <i>Archive event</i> button.</p>	<p>The Anonymous event disappears from the system. Anonymous events overview page is shown on the main screen with the updated list.</p>

Table 47, instructions on how to delete (archive) an anonymous event

## Abbreviations

Abbreviation	Full term
EBMT	European Society for Blood and Marrow Transplantation
Allo-HCT	Allogeneic HCT
Auto-HCT	Autologous HCT
CT	Cellular therapy
CIC	Centre Identification Code, see more in <a href="#">Centre</a> section
ICF	Informed consent form
IST	Immunosuppressive therapy
MFA	Multi-factor authentication
OMOP CDM	Observational Medical Outcomes Partnership Common Data Model
DCF	Data collection form
VR	Virtual registry
UPN	Unique patient number, see more in <a href="#">Patient</a> section

Table 48, abbreviations

## Appendix 1: Treatment\_overview

This Appendix explains the content of the treatment\_overview file. The analytical export contains a set of core items that can be used for quick analyses of the data. The file was custom made for EBMT, and does not follow the OMOP format. It is similar to a transplant listing, containing all registered procedures (HCT, CT, IST) that a patient underwent.

Column name	Description
person_id	This is the identifier used in the OMOP tables; use this ID to link tables to each other
person_source_value	This is the long ID as used in the EBMT Registry
short_patient_id	This is the short patient ID as used in the EBMT Registry
promise_patient_id	This column contains the ProMISe patient ID, if the patient was migrated
first_name	This column contains the initials of the patient's first name
last_name	This column contains the initials of the patient's last name
year_of_birth	This column contains the person's year of birth
month_of_birth	This column contains the person's month of birth, if completed
day_of_birth	This column contains the person's day of birth, if completed
gender_concept_id	This column contains the OMOP value of the person's sex at birth
gender_concept_name	This column contains the verbatim sex at birth
registration_cic	This column contains the id of the centre that registered the patient, as used in the EBMT Registry. This is the CIC
treating_cic	This column contains the id of the centre where the treatment (procedure) took place, as used in the EBMT Registry. This is not necessarily the CIC of the registration centre
treating_upn	This is the UPN of the patient in the centre where the treatment took place
condition_concept_id	This is the OMOP concept for the diagnosis for which the procedure (treatment) was given. It will appear empty if the treatment was not properly linked to the diagnosis event

Column name	Description
condition_source_value	This column contains the diagnosis event that was the reason for this treatment. It will appear empty if the treatment was not properly linked to the diagnosis event
condition_start_date	This column contains the date of the diagnosis (condition)
pcd_classification_concept_id	This is the OMOP concept of the subclassification of the plasma cell disorder, if the patient received a treatment for PCD
pcd_classification_source_value	This is the verbatim OMOP concept of the subclassification
mpn_classification_concept_id	This is the OMOP concept of the subclassification of the myeloproliferative neoplasm, if the patient received a treatment for MPN
mpn_classification_source_value	This is the verbatim OMOP concept of the subclassification
mds_classification_concept_id	This is the OMOP concept of the subclassification of the myelodysplastic syndrome, if the patient received a treatment for MDS
mds_classification_source_value	This is the verbatim OMOP concept of the subclassification
mdsmpn_classification_concept_id	This is the OMOP concept of the subclassification of the MDS/MPN, if the patient received a treatment for MDS/MPN
mdsmpn_classification_source_value	This is the verbatim OMOP concept of the subclassification
cl_classification_concept_id	This is the OMOP concept of the subclassification of the chronic leukemia, if the patient received a treatment for chronic leukemia
cl_classification_source_value	This is the verbatim OMOP concept of the subclassification
al_classification_concept_id	This is the OMOP concept of the subclassification of the acute leukemia, if the patient received a treatment for acute leukemia
al_classification_source_value	This is the verbatim OMOP concept of the subclassification
pln_classification_concept_id	This is the OMOP concept of the subclassification of the precursor lymphoid neoplasm (formerly known as ALL), if the patient received a treatment for PLN

Column name	Description
pln_classification_source_value	This is the verbatim OMOP concept of the subclassification
oal_classification_concept_id	This is the OMOP concept of the subclassification of the other acute leukaemia, if the patient received a treatment for an other acute leukaemia
oal_classification_source_value	This is the verbatim OMOP concept of the subclassification
lymphoma_classification_concept_id	This is the OMOP concept of the subclassification of the lymphoma, if the patient received a treatment for lymphoma
lymphoma_classification_source_value	This is the verbatim OMOP concept of the subclassification
b_nhl_classification_concept_id	This is the OMOP concept of the subclassification of the B-cell non-Hodgkin lymphoma, if the patient received a treatment for B-cell lymphoma
b_nhl_classification_source_value	This is the verbatim OMOP concept of the subclassification
t_nhl_classification_concept_id	This is the OMOP concept of the subclassification of the T-cell non-Hodgkin lymphoma, if the patient received a treatment for T-cell lymphoma
t_nhl_classification_source_value	This is the verbatim OMOP concept of the subclassification
hodgkin_classification_concept_id	This is the OMOP concept of the subclassification of the Hodgkin lymphoma, if the patient received a treatment for a Hodgkin lymphoma
hodgkin_classification_source_value	This is the verbatim OMOP concept of the subclassification
id_lym_classification_concept_id	This is the OMOP concept of the subclassification of the immunodeficiency-associated lymphoproliferative disorder, if the patient received a treatment for this
id_lym_classification_source_value	This is the verbatim OMOP concept of the subclassification
solidtumours_classification_concept_id	This is the OMOP concept of the subclassification of the solid tumour, if the patient received a treatment for a solid tumour
solidtumours_classification_source_value	This is the verbatim OMOP concept of the subclassification

Column name	Description
inborerrors_classification_concept_id	This is the OMOP concept of the subclassification of the inborn error, if the patient received a treatment for an inborn error
inborerrors_classification_source_value	This is the verbatim OMOP concept of the subclassification
ieimmunity_classification_concept_id	This is the OMOP concept of the subclassification of the inborn error of immunity, if the patient received a treatment for an inborn error of immunity
ieimmunity_classification_source_value	This is the verbatim OMOP concept of the subclassification
cid_ieimmunity_classification_concept_id	This is the OMOP concept of the subclassification of the combined immune deficiency, if the patient received a treatment for a combined immune deficiency
cid_ieimmunity_classification_source_value	This is the verbatim OMOP concept of the subclassification
pad_ieimmunity_classification_concept_id	This is the OMOP concept of the subclassification of the predominantly antibody deficiency, if the patient received a treatment for a predominantly antibody deficiency
pad_ieimmunity_classification_source_value	This is the verbatim OMOP concept of the subclassification
dysregu_ieimmunity_classification_concept_id	This is the OMOP concept of the subclassification of the disease of immune dysregulation, if the patient received a treatment for a disease of immune dysregulation
dysregu_ieimmunity_classification_source_value	This is the verbatim OMOP concept of the subclassification
phagocyt_ieimmunity_classification_concept_id	This is the OMOP concept of the subclassification of the phagocyte defect, if the patient received a treatment for a phagocyte defect
phagocyt_ieimmunity_classification_source_value	This is the verbatim OMOP concept of the subclassification
intrinsic_innate_ieimmunity_classification_concept_id	This is the OMOP concept of the subclassification of the defects of intrinsic and innate immunity, if the patient received a treatment for a defect of intrinsic and innate immunity
intrinsic_innate_ieimmunity_classification_source_value	This is the verbatim OMOP concept of the subclassification

Column name	Description
autoinflam_ieimmunity_classification_concept_id	This is the OMOP concept of the subclassification of the autoinflammatory disorders, if the patient received a treatment for an autoinflammatory disorder
autoinflam_ieimmunity_classification_source_value	This is the verbatim OMOP concept of the subclassification
iemetabolism_classification_concept_id	This is the OMOP concept of the subclassification of the inborn errors of metabolism, if the patient received a treatment for an inborn error of metabolism
iemetabolism_classification_source_value	This is the verbatim OMOP concept of the subclassification
mpps_iemetabolism_classification_concept_id	This is the OMOP concept of the subclassification of MPS, if the patient received a treatment for MPS
mpps_iemetabolism_classification_source_value	This is the verbatim OMOP concept of the subclassification
other_lsd_iemetabolism_classification_concept_id	This is the OMOP concept of the subclassification of the lysosomal storage diseases, if the patient received a treatment for a lysosomal storage disease
other_lsd_iemetabolism_classification_source_value	This is the verbatim OMOP concept of the subclassification
other_nonlsd_iemetabolism_classification_concept_id	This is the OMOP concept of the subclassification of the other (non-MDS) lysosomal storage diseases, if the patient received a treatment for an other lysosomal storage disease
other_nonlsd_iemetabolism_classification_source_value	This is the verbatim OMOP concept of the subclassification
otherie_classification_concept_id	This is the OMOP concept of the subclassification of the other inborn errors of metabolism, if the patient received a treatment for an other inborn error of metabolism
otherie_classification_source_value	This is the verbatim OMOP concept of the subclassification
haemoglob_classification_concept_id	This is the OMOP concept of the subclassification of the haemoglobinopathies, if the patient received a treatment for an haemoglobinopathy
haemoglob_classification_source_value	This is the verbatim OMOP concept of the subclassification

Column name	Description
bmf_classification_concept_id	This is the OMOP concept of the subclassification of the bone marrow failures, if the patient received a treatment for a bone marrow failure
bmf_classification_source_value	This is the verbatim OMOP concept of the subclassification
acquiredbmf_classification_concept_id	This is the OMOP concept of the subclassification of the acquired bone marrow failures, if the patient received a treatment for an acquired bone marrow failure
acquiredbmf_classification_source_value	This is the verbatim OMOP concept of the subclassification
geneticbmf_classification_concept_id	This is the OMOP concept of the subclassification of the genetic bone marrow failures, if the patient received a treatment for a genetic bone marrow failure
geneticbmf_classification_source_value	This is the verbatim OMOP concept of the subclassification
autoimmune_classification_concept_id	This is the OMOP concept of the subclassification of the autoimmune diseases, if the patient received a treatment for an autoimmune disease
autoimmune_classification_source_value	This is the verbatim OMOP concept of the subclassification
connective_ad_classification_concept_id	This is the OMOP concept of the subclassification of the connective tissue autoimmune diseases, if the patient received a treatment for a connective tissue disease
connective_ad_classification_source_value	This is the verbatim OMOP concept of the subclassification
vaculitis_ad_classification_concept_id	This is the OMOP concept of the subclassification of the vasculitis autoimmune diseases, if the patient received a treatment for vasculitis
vaculitis_ad_classification_source_value	This is the verbatim OMOP concept of the subclassification
arthritis_ad_classification_concept_id	This is the OMOP concept of the subclassification of the arthritis autoimmune diseases, if the patient received a treatment for arthritis
arthritis_ad_classification_source_value	This is the verbatim OMOP concept of the subclassification



Column name	Description
neurological_ad_classification_concept_id	This is the OMOP concept of the subclassification of the neurological autoimmune diseases, if the patient received a treatment for a neurological autoimmune disease
neurological_ad_classification_source_value	This is the verbatim OMOP concept of the subclassification
haematological_ad_classification_concept_id	This is the OMOP concept of the subclassification of the haematological autoimmune diseases, if the patient received a treatment for an haematological autoimmune disease
haematological_ad_classification_source_value	This is the verbatim OMOP concept of the subclassification
inf_bowel_ad_classification_concept_id	This is the OMOP concept of the subclassification of the inflammatory bowel autoimmune diseases, if the patient received a treatment for an inflammatory bowel autoimmune disease
inf_bowel_ad_classification_source_value	This is the verbatim OMOP concept of the subclassification
other_ad_classification_concept_id	This is the OMOP concept of the subclassification of the other autoimmune diseases, if the patient received a treatment for an other neurological autoimmune disease
other_ad_classification_source_value	This is the verbatim OMOP concept of the subclassification
procedure_nb_hct_value_as_number	This is the chronological number of this HCT procedure
procedure_concept_id	This column contains the value of the OMOP concept of the procedure
procedure_source_value	This column contains the type of procedure verbatim
procedure_date	This column contains the date of the procedure (e.g. HCT event date)
cell_infusion_confirmed_concept_id	This column is only applicable for cell therapy treatments. It contains the OMOP concept for if the apheresed cells were infused or not.
cell_infusion_confirmed_source_value	This column is only applicable for cell therapy treatments. It contains the verbatim OMOP concept for if the apheresed cells were infused or not.

Column name	Description
survival_status_date	This is the date of the last survival status that was reported most recently (i.e. on the last follow-up where the item was completed). Note: if 'EBMT export error conflict' is shown, check the patient on the frontend. The error shows if conflicting data was entered.
survival_status_concept_id	This is the OMOP concept of the person's survival status that was reported most recently (i.e. on the last follow-up where the item was completed)
survival_status_source_value	This is the verbatim OMOP concept of the survival status
maincause_death_concept_id	This column contains the OMOP concept of main cause of death reported at the last follow-up where the patient was reported as dead.
maincause_death_source_value	This column contains the verbatim OMOP concept of main cause of death reported at the last follow-up where the patient was reported as dead.
patient_event_id_diagnosis	This column contains the identifier of the patient's diagnosis event in the EBMT Registry.
patient_event_id_treatment	This column contains the identifier of the patient's treatment event that generated this row, in the EBMT Registry.
pipeline_version	This column has the version of the pipeline that was used to generate the treatment overview. It cannot be used for analyses but should be used when reporting issues or questions about the treatment_overview.

Table 8, treatment\_overview file: table names and content