

Migration issues

After the EBMT Registry go-live, users reported to the Helpdesk about inconsistencies found in data migration to the EBMT Registry. This document summarises the known issues per event, and steps taken or planned to resolve it.

Patient

- Missing patient - centre links: if a patient was linked to multiple centres, the links to other centres than the centre that registered the patient in ProMISe were missing.
 - **Resolution:** links have been migrated in August 2024.
- Missing consent date and UPNs: it was not migrated if this data was registered only in CASTOR, only corresponding variables from ProMISe were migrated to the EBMT Registry.
 - **Resolution:** The EBMT is investigating how to resolve this.
- Missing information about studies: due to the structure of questions “Participation in national/international study/trial (not EBMT Study)?” and “Study name” being a single text field, it was not possible to migrate multiple studies.
 - **Resolution:** the study section will be transformed into a repeatable group in upcoming versions of the EBMT Registry, subsequently the data will be migrated from ProMISe.
- Data from the field “Patient ID in conversion source” was not migrated.
 - **Resolution:** this data will be migrated as part of Core dataset migration v1 fix.

Anonymous events

- Due to late confirmation of patient consent, anonymous events were created for patients’ profiles migrated last-minute or in later cycles.
 - **Resolution:** such anonymous events were archived in February 2025.

Diagnosis

Acute leukaemia

- The WHO Classification for ALL & AML missing.
 - **Resolution:** the WHO classification was migrated in August 2024.

Autoimmune disorders

- Other previous therapies question and the text field “Other previous therapy: specify” was not a repeatable group, allowing only 1 “other” previous therapy to be entered.

- **Resolution:** the field was updated, and the data was migrated in August 2024.

Bone marrow failures

- “Paroxysmal nocturnal haemoglobinuria (PNH)” had radio group answer options, while it should have been a checkbox.
 - **Resolution:** the field was updated, and information was migrated in August 2024.
- “Chromosome analysis complete karyotype” question missing, data in these fields was not migrated.
 - **Resolution:** field was added and data migrated in August 2024.

Chronic leukaemias

- Previous therapy start and end dates were in repeatable groups, while they should have been standalone questions.
 - **Resolution:** the field was updated, and information was migrated in August 2024.

MDS

- FAB classification at diagnosis was not migrated.
 - **Resolution:** the question was added as an inactive question and legacy data was migrated in August 2024.

Treatment

Status at HCT/CT/IST

- The comorbidity pulmonary: if in ProMISe the response to the question “Pulmonary comorbidity” (PULMONC) was “Present” without specification of severity (Mild, Moderate or Severe), this data was not migrated to the new questions in the EBMT Registry, since it cannot be used for calculation of the comorbidity score.
 - **Resolution:** if users were registering patient data without specifying the severity of the pulmonary comorbidity, please amend the corresponding forms in the EBMT Registry by answering the question “Pulmonary: severe” and “Pulmonary: moderate” in the section Comorbidity Index. If you need assistance identifying those patients, please reach out to the Helpdesk.

Allogeneic HCT

- Donor blood group information was not migrated

- **Resolution:** this data will be migrated together with the first migration cycle of the extended dataset.

Cellular therapy

- Cellular therapy data was migrated from ProMISe to Castor prior to the migration from Castor to the EBMT Registry. However, in cases where the cellular therapy was not a CAR-T (ex. TIL (tumor-infiltrating lymphocytes), MSC (mesenchymal stem cell) therapies), or the patient had HIDEREG (“Temporarily hide registration”) or EBMTREG (“Exclude from EBMT registry”) filled, the treatment was not migrated. This affects 390 cellular therapies.
 - **Resolution:** the EBMT is currently investigating what can be done to complete the cellular therapy information in the EBMT Registry.
- Some items that were completed in ProMISe or Castor are not migrated to the EBMT Registry. It concerns “Indication for planned cellular therapy”, “Will the planned cellular infusion product consist of more than one infusion unit?”, “Is the planned cell infusion product a commercial product?”
 - **Resolution:** the EBMT is investigating how to best resolve this.

Follow-up

HCT Day 100 and annual

- Due to the changes in the DCF question about relapse and the way data was collected in ProMISe, relapse instances have been migrated as false positives if the answer to “Relapse or progression after transplant” was ‘Yes, before this date’.
 - Resolution: the EBMT is planning to resolve this in the future.
- The ProMISe variable for date of relapse presence or absence evaluation was migrated as date of relapse.
 - Resolution: the EBMT is planning to resolve this in the future.
- If the relapse information was entered on the transplant assessment instead of on a follow-up assessment, the relapse date was wrongly migrated.
 - **Resolution:** EBMT is looking into a solution that replaces the migrated data with correct information.
- DLI information and data about some additional treatments with drugs are missing.
 - **Resolution:** EBMT is looking into a solution that replaces the migrated data with correct information.
- Extra events were created which were not meant to be independent follow-ups, and HCT follow-ups appear after CTs or duplicating the existing CT follow-ups (HCT and CT follow-up

events on the same date). Some of the data, which was reported in ProMISe assessments used to create such events, is missing in the EBMT Registry.

- **Resolution:** EBMT in collaboration with the vendors will restore the lost data in meaningful events and will archive empty follow-up events or the ones which duplicate the CT follow-ups.

Cellular therapy follow up

- The follow-ups that were reported previously have been migrated as duplicate events on the patient timelines, if multiple cellular therapies were entered without a follow-up assessment in between. For example if a patient had a cellular therapy, and later a second one, and follow-up data was only added for the second one. Then this follow up would be duplicated.
 - **Resolution:** if the patient has duplicate CT follow-up events we ask Data Managers to archive one of those and combine the information in a single Cellular Therapy follow-up