

# Donor long-term outcome

**Guide to the completion of the EBMT data  
collection form:**

**Donor\_Long\_Term\_Outcome\_v1.0**

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**EBMT Registry**

EBMT Clinical Research & Registry Department



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## Long-term donor outcomes

The first submission of this form should be done as soon as 6 months has passed from the date of the donation procedure. After that, we recommend that it should be submitted every two years up to 10 years. If this is not possible, the minimum submission should be after 5 years and again after 10 years

If a donor has done multiple donations, it is not necessary to report long term follow-up per each donation. The long-term follow-up for the latest donation should be provided.

If a donor dies, this report should be submitted outside of the stated above timelines as soon as the fact of death becomes known.

## Donor status

### 1. Date of this follow-up

Report the follow-up date for the last donation procedure. If the donor died or was lost to follow-up, enter the date the donor was last seen alive.

### 2. Donor status at follow-up

Indicate if the donor is last known to be **Alive** or **Dead**.

If the donor is lost to follow-up, check the box **Lost to follow-up**. When indicating Lost to follow up, the date of the last contact should be the last date that it is known for sure the donor was alive. This answer option should only be used if:

- Any contact with the donor has been lost (follow the guidelines of your centre on how many attempts to contact the donor have to be done for this status to be acceptable);
- The donor refused to be followed up.

Answer the following sub question only if the donor died:

#### 2.1. Donation related:

Answer **Yes** if the donor died because of donation related reasons.

Select **No** if donor death is not related to donation.

If it is unknown if the donor died due to donation related reasons or not, select Unknown.

#### 2.2. Date of death:

Report the date the donor died.

#### 2.3. ICD code for main cause of death (select only one):

Select the ICD code for the main cause of death. The ICD codes can be found on the [WHO ICD website](#).

#### 2.4. ICD code(s) for contributory causes of death:

Report the ICD code(s) for contributory causes of death. The ICD codes can be found on the [WHO ICD website](#).

#### 2.5. ICD version used:

Select the ICD version which was used for this report.

#### 2.6. Further description of cause of death (if necessary):

If needed, provide further details on the donor cause of death in the text field in English.

## Collection centre identification

### 3. EBMT Centre Identification Code (CIC):

Report, if known, the CIC number of the centre or donor registry where the collection took place.

### 4. Collection centre:

Report the full name of the collection centre, including city and country.

### 5. Donor registry:

Only for unrelated donors, report the full name of the donor registry that collected material. If available, add also the BMDW/WMDA code which can be found at: <https://statistics.wmda.info/>

### 6. Contact person:

Report the name of the person who can be contacted for further questions about the collection.

## Product

### 7. Donated product:

Select the checkbox to specify which product was donated to the recipient:

- **BM (including collection of MSC)**
- **PBSC**
- **Both, BM and PBSC**
- **Unstimulated leukapheresis** (e.g. lymphocytes (DLI), etc.)

## Complications (sae/sar) since last report

### 8. Haematological malignancy?

If haematological malignancies did not occur since the last report, answer **No**. If it is not known whether or not haematological malignancy occurred since the last report, select **Unknown**. If haematological malignancy did occur since the last report, select **Yes** and answer the following sub questions for each occurred haematological malignancy.

#### 8.1. ICD code:

Report the ICD code for this haematological malignancy. The ICD codes can be found on the WHO ICD website.

#### 8.2. Specify:

Specify which type of haematological malignancy occurred. There are three main types of haematological malignancies: leukaemia, lymphoma and plasma cell disorder. Specification with the ICD for the detailed information of the subtype is very important.

#### 8.3. ICD version used:

Specify the ICD version which was used for this reporting.

#### 8.4. Onset date:

Report the onset date the haematological malignancy occurred if known.

#### 8.5. Confirmed by medical data:

Select Yes if medical records confirming the haematological malignancy are available. If it has not been confirmed with medical records, select **No**. If it is unclear whether or not it has been confirmed, select **Unknown**.

### 9. Non-haematological malignancy?

If non-haematological malignancies did not occur since the last report, answer **No**. If it is not known whether or not non-haematological malignancy occurred since the last report, select Unknown. If non-haematological malignancy did occur since the last report, select Yes and answer the following sub questions for each occurred non-haematological malignancy.

#### 9.1. ICD code:

Report the ICD code for this non-haematological malignancy. The ICD codes can be found on the [WHO ICD website](#).

9.2. Specify:

Specify which type of non-haematological malignancy occurred.

9.3. ICD version used:

Specify the ICD version which was used for this reporting.

9.4. Onset date

Report the onset date the non-haematological malignancy occurred if known.

9.5. Confirmed by medical data:

Select Yes if medical records confirming the non-haematological malignancy are available. If it has not been confirmed with medical records, select **No**. If it is unclear whether or not it has been confirmed, select **Unknown**.

## 10. Autoimmune disease?

If an autoimmune disease did not form since last report, select **no**. If it is not known whether or not autoimmune disease occurred since last report, select **unknown**. If autoimmune disease did occur since the last report, select **yes** and answer the following questions.

10.1 ICD code:

Report the ICD code for this autoimmune disease. The ICD codes can be found on the [WHO ICD website](#).

10.2. Specify:

Specify which type of autoimmune disease occurred.

10.3. ICD version used:

Specify the ICD version which was used for this reporting.

10.4. Onset date:

Report the onset date the autoimmune disease occurred if known.

10.5. Confirmed by medical data:

Is the autoimmune disease confirmed by medical data? Select **Yes** if medical records confirming the autoimmune disease are available. If it has not been confirmed with medical records, select **No**. If it is unclear whether or not it has been confirmed, select **Unknown**.

## Donor behaviour

## 11. Would the donor donate again?

Based on the donor questionnaire or answer, report here donor experience and behaviour.

If the donor would not donate again in the future, select **No** and specify the reason why the donor would not donate again in the text field in English.

If the donor would donate again, select **Yes**.

If it is not known whether or not the donor would donate again, select **Unknown**.

## Comments:

If there are any additional notes to this procedure, specify them in the text field in English.