

Donor outcome long-term

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

Donor_Long_Term_Outcome_v1.1

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EBMT Registry

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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

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.

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:

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**.

Date of death

Report the date the donor died. If the date is not known mark it as **Unknown**.

ICD code for main cause of death (select only one)

Select the ICD code of the main cause of death from a dropdown list. If the matching code can not be found select Other and specify the ICD code in the text field.

Other ICD code for main cause of death

The ICD codes can be found on the [WHO ICD website](#).

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](#).

ICD version used

Select the ICD version which was used for this report.

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.

Complications (SAE/SAR) since last report

IMPORTANT NOTE

Unrelated donors: WMDA SEAR reporting

Reporting to WMDA is **mandatory for WMDA accredited registries** and highly recommended for all other registries.

Please go to WMDA website: <https://wmda.info/>

· Click on the left side: S(P)EAR Committee How to report S(P)EAR to the WMDA for information · Follow the link to the online reporting system:

<http://www.surveygizmo.com/s3/720793/SEAR-and-SPEAR-2012>

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.

ICD code

Select the ICD code of the haematological malignancy from a dropdown list. If the matching code can not be found select Other and specify the ICD code in the text field.

Other ICD code

The ICD codes can be found on the [WHO ICD website](#).

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.

ICD version used

Specify the ICD version which was used for this reporting.

Onset date

Report the onset date the haematological malignancy occurred if known. If the date is not known, mark as **Unknown**.

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**.

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.

ICD code

Select the ICD code of the non-haematological malignancy from a dropdown list. If the matching code can not be found select Other and specify the ICD code in the text field.

Other ICD code

The ICD codes can be found on the [WHO ICD website](#).

Specify

Specify which type of non-haematological malignancy occurred.

ICD version used

Specify the ICD version which was used for this reporting.

Onset date

Report the onset date the non-haematological malignancy occurred if known. If the date is not known, mark as **Unknown**.

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**.

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.

ICD code

Select the ICD code of the autoimmune disease from a dropdown list. If the matching code can not be found select **Other** and specify the ICD code in the text field.

Other ICD code

The ICD codes can be found on the [WHO ICD website](#).

Specify

Specify which type of autoimmune disease occurred.

ICD version used

Specify the ICD version which was used for this reporting.

Onset date

Report the onset date the autoimmune disease occurred if known. If the date is not known, mark as **Unknown**.

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

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.