2900: Recipient Death

The Recipient Death Data (Form 2900) captures cause of death data fields for recipients on the on the Comprehensive Report Form and Cellular Therapy Essential Data follow-up tracks. The leading cause of post-transplant mortality is persistent, recurrent, or relapsed primary disease. Other common causes of death include graft-versus-host disease, infection, and organ failure. As hematopoietic cell transplant and cellular therapy evolves, reporting accurate cause of death data is important to investigating the variables that are associated with post-infusion outcomes.

If **Dead** is reported as the current survival status at the date of last contact on the Post-TED (2450), Post-HCT Follow-Up (2100) or Cellular Therapy Essential Data Follow-Up (4100) form at the 100-day, six month, and yearly time points, complete the Recipient Death Data (2900) as soon as possible after the recipient has died.

> ! **Do not complete the Recipient Death Data (Form 2900) for Autologous recipients who did not consent to be a part of the research database.**

Lost to Follow-Up

Occasionally, centers may lose contact with recipients for a variety of reasons, including the recipient's moving, changing physicians, or death. After attempts to contact the recipient or referring physician have failed, the recipient may be declared lost to follow-up. If your center later receives documentation that a recipient is dead, report this on the appropriate follow-up form for the time period in which the recipient died. This may require resetting of a form that was previously made Lost to Follow Up (LTF) or Survival (SUR). This may happen when a center becomes aware of the death after it has reported that the recipient is lost to follow-up. To reset the form, click the blue counterclockwise arrow icon.

Q1-7: Recipient Death Data
Cause of Death Codes

Manual Updates:
Sections of the Forms Instruction Manual are frequently updated. The most recent updates to the manual can be found below. For additional information, select the manual section and review the updated text.

If you need to reference the historical Manual Change History for this form, you can reference the retired manual section on the Retired Forms Manuals webpage.

Date	Manual Section	Add/ Remove/ Modify	Description
4/3/ 2024	2900: Recipient	Modify	Instructions for LTF updated due to centers now being able to reset LTF forms on their own: *Occasionally, centers may lose contact with recipients for a variety of*

	Death		*reasons, including the recipient's moving, changing physicians, or death. After attempts to contact the recipient or referring physician have failed, the recipient may be declared lost to follow-up. If your center later receives documentation that a recipient is dead, report this on the appropriate follow-up form for the time period in which the recipient died. This may require resetting of a form that was previously made Lost to Follow Up (LTF) or Survival (SUR). ~~contacting CIBMTR Center Support to open a form for completion. For example,~~ %(color-red)This may happen when a center ~~may only~~ becomes aware of the death after it has reported that the recipient is lost to follow-up. To reset the form, click the blue counterclockwise arrow icon. ~~If a recipient dies a year and a half after transplant with no contact at your center, and a lost to follow-up form is completed for the two-year time point, submit a ticket through CIBMTR Center Support to make the two-year follow-up form due.~~*
2/12/2024	2900: Recipient Death	Add	Instructions for when 'autopsy pending' is reported were updated: *If **Autopsy pending**, the form will not go to complete (CMP) status until the autopsy results are reported. The form may be submitted with question 2 as **Autopsy pending**, but the form will remain in saved (SVD) status until it is updated with the results. Once the autopsy results are known, update question 2, and the **Primary cause of death**, if applicable, to ensure all pertinent causes of death are reported, then resubmit in order to complete the form. All pertinent causes of death should be reported on the second Recipient Death Data (2900) form.*
2/15/2023	2900: Recipient Death	Add	The 'No Documentation of Contact Date' red warning box added above Q1: ***No Documentation of Contact Date*** *The contact date data field cannot be left blank and is required to be reported. In cases where the recipient passed away and there is no documentation to report the date of death, the guidelines for reporting estimated dates must be used.*
2/28/2022	2900: Recipient Death	Modify	Instructions for when 'autopsy pending' is reported were updated due to changes made during the Spring 2021 release: *If Autopsy pending, ~~continue with question 4. Report the cause of death as determined by a physician. A second Recipient Death Data (2900) form will become due six months from the date of death to report any additional cause of death information found during autopsy.~~ the form will not go to complete (CMP) status until the autopsy results are reported. The form may be submitted with question 2 as **Autopsy pending**, but the form will remain in saved (SVD) status until it is updated with the results. Once the autopsy results are known, update question 2 and resubmit in order to complete the form. All pertinent causes of death should be reported on the second Recipient Death Data (2900) form.*
10/29/2021	2900: Recipient Death	Modify	Version 4 of the 2900: Recipient Death section of the Forms Instructions Manual released. Version 4 corresponds to revision 5 of the Form 2900.

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Q1-7: Recipient Death Data

> **No Documentation of Death Date**
> The death date data field cannot be left blank and is required to be reported. In cases where the recipient passed away and there is no documentation to report the date of death, the guidelines for reporting estimated dates must be used.

Question 1: Date of Death

Report the date the recipient died. Confirm that the date matches the last date of actual contact reported on the Post-TED (2450), Post-Infusion Follow-Up (2100) form or Cellular Therapy Essential Data Follow-Up (4100) form.

If the death occurred at an outside location and records of death are not available, the dictated date of death within a physician note may be reported. If the progress notes detailing the circumstances of death are available, request these records. These records are useful for completing required follow-up data fields on the Form 2100 or Form 4100 and the cause of death data fields on this form.

If the exact date of death is not known, use the process described for reporting partial or unknown dates in General Instructions, Guidelines for Completing Forms

Question 2: Was cause of death confirmed by autopsy?

Indicate if the cause of death was confirmed by autopsy.

If **Autopsy pending**, the form will not go to complete (CMP) status until the autopsy results are reported. The form may be submitted with question 2 as **Autopsy pending**, but the form will remain in saved (SVD) status until it is updated with the results. Once the autopsy results are known, update question 2 and the **Primary cause of death**, if applicable, to ensure all pertinent causes of death are reported, then resubmit in order to complete the form.

Question 3: Was documentation submitted to the CIBMTR? (autopsy report)

Indicate if a documentation (i.e., copy of the autopsy report) was submitted to the CIBMTR.

For further instructions on how to attach documents in FormsNet3SM, refer to the training guide.

> **Sepsis and Septic Shock**: ‘Sepsis’ and ‘septic shock’ should not be reported in the *other* data field as the true cause of death is an infection. If the cause of death is ‘sepsis,’ select **Infection**.

Primary Cause of Death
Report the primary cause of death based on the physician's determination. If the cause of death is unclear, seek physician clarification to determine the appropriate cause of death.

Questions 4-5: Primary cause of death

Report the underlying cause of death. According to the Centers for Disease Control and Prevention, National Center for Health Statistics, the underlying cause of death is "the disease or injury that initiated the chain of events that led directly or inevitably to death."

Report only one primary cause of death. Options which require additional specification include **Other infection**, **Other pulmonary syndrome**, **Multiple organ failure**, **Other organ failure**, **Other hemorrhage**, **Other vascular**, and **Other cause**. Information reported in the specify field must pertain to the option selected (e.g., an infectious cause of death should be specified for **Other infection**).

If the recipient has recurrent / persistent / progressive disease at the time of death, consider if the disease was the primary cause of death or a contributing cause of death. It should not be assumed that the presence of disease indicates that the disease was the primary cause of death.

If a cause of death has related questions on the comprehensive report form, report the appropriate data in both locations. For example, if a primary cause of death was infection, complete the infection data fields on the comprehensive report form.

If the primary cause of death is unclear, consult with a physician for their best medical opinion.

Questions 6-7: Contributing cause of death

Report any additional causes of death. All contributing causes of death are important for analysis of transplant outcomes.

Options which require additional specification include **Other infection**, **Other pulmonary syndrome**, **Multiple organ failure**, **Other organ failure**, **Other hemorrhage**, **Other vascular**, and **Other cause**. Information reported in the specify field (question 7) must pertain to the option selected (e.g., an infectious cause of death should be specified for **Other infection**).

If a cause of death has related questions on the comprehensive report form, report the appropriate data in both locations. For example, if a contributing cause of death was acute graft-versus-host disease (GVHD), complete the acute GVHD data fields on the comprehensive report form.

If there were multiple contributing causes of death, enable an additional instance to report additional causes.

Review the examples below on how to report primary and contributing cause of death:

Example 1: In the 1-year reporting period, a recipient transplanted for AML has relapsed disease that leads to multiple organ failure. In this scenario, the primary cause of death should be captured as relapsed disease and the contributing cause of death should be reported as multiple organ failure.

Example 2: A recipient with acute GVHD on immunosuppression develops a fungal infection and then dies. In this scenario, the primary cause of death should be reported as acute GVHD and the contributing cause of death would be captured as a fungal infection.

Section Updates:

Question Number	Date of Change	Add/ Remove/ Modify	Description	Reasoning (If applicable)
Q1	2/15/ 2023	Add	The 'No Documentation of Contact Date' red warning box added: ***No Documentation of Contact Date*** *The contact date data field cannot be left blank and is required to be reported. In cases where the recipient passed away and there is no documentation to report the date of death, the guidelines for reporting estimated dates must be used.*	Added for clarification
Q1	7/22/ 2022	Modify	Instructions for Q1 updated: _Report the date the recipient died. Confirm that the date matches the last date of actual contact reported on the Post-TED (2450), Post-Infusion Follow-Up (2100) form or Cellular Therapy Essential Data Follow-Up (4100) form. If the death occurred at an outside location and records of death are not available, the dictated date of death within a physician note may be reported. If the progress notes detailing the circumstances of death are available, request these records. These records are useful for completing required follow-up data fields on the ~~Form 2100 or Form 4100~~ Post-TED (2450), Post-Infusion Follow-Up (2100) form or Cellular Therapy Essential Data Follow-Up (4100) form and the cause of death data fields on this form.	Due to changes made during the Summer 2022 release – the 2900 is now completed for TED, CRF, and CT track.
Q2	2/12/ 2024	Modify	Instructions for when 'autopsy pending' is reported were updated: *If **Autopsy pending**, the form will not go to complete (CMP) status until the autopsy results are reported. The form may be submitted with question 2 as **Autopsy pending**, but the form will remain in saved (SVD) status until it is updated with the results. Once the autopsy results are known, update question 2, and the **Primary cause of death**, if applicable, to ensure all pertinent causes of death are reported, then resubmit in order to complete the form. All pertinent causes of death should be reported on the second Recipient Death Data (2900) form.*	Added for clarification

Q2	2/28/ 2022	Modify	Instructions for when 'autopsy pending' is reported were updated: *If Autopsy pending, ~~continue with question 4. Report the cause of death as determined by a physician. A second Recipient Death Data (2900) form will become due six months from the date of death to report any additional cause of death information found during autopsy.~~ the form will not go to complete (CMP) status until the autopsy results are reported. The form may be submitted with question 2 as **Autopsy pending**, but the form will remain in saved (SVD) status until it is updated with the results. Once the autopsy results are known, update question 2 and resubmit in order to complete the form. All pertinent causes of death should be reported on the second Recipient Death Data (2900) form.*	Due to changes made during the Spring 2021 release – a second 2900 is no longer required when an autopsy is pending.

Last modified: Jan 27, 2025

Cause of Death Codes

Recurrence / persistence / progression of disease for which the HCT or cellular therapy was performed

If the disease is present at death, but not the underlying cause of death, “Recurrence/persistence/ progression of disease for which the HCT or cellular therapy was performed” should be reported as a contributing cause of death. For example, if a recipient’s disease had been stable for months and the recipient died by accidental means, this option should be used as a contributing cause of death (not the primary cause of death).

Acute versus Chronic GVHD
In the past, GVHD was classified as acute or chronic based on when it was diagnosed following transplant, as well as other clinical and histological (biopsy or post-mortem) features. Today, there is increased recognition that acute and chronic GVHD are not dependent upon the time since HCT, so *determination of acute versus chronic should rest on clinical and histological features identified by the clinician.*

Acute GVHD

If reported as a primary or contributing cause of death, acute GVHD should also be reported on the appropriate Post-Infusion Follow-Up (2100) form.

Chronic GVHD

If reported as a primary or contributing cause of death, chronic GVHD should also be reported on the appropriate Post-Infusion Follow-Up (2100) form..

Graft rejection or failure

The recipient had no hematopoietic recovery or had graft failure following initial hematopoietic recovery. If secondary graft failure is due to GVHD or infection, also report GVHD or infection as causes of death.

Cytokine release syndrom (CRS)

CRS occurs when there is a systemic inflammatory response as the result of immunotherapy (i.e. CAR T-cell therapy). In severe cases, it’s also known as “Cytokine storm.”

Hemorrhage

If the recipient died with evidence of hemorrhage, use the cause of death options to report its location. If the hemorrhage was in an organ system that does not have a cause of death option, use **Other hemorrhage**, and report the organ or location of the hemorrhage.

Pulmonary hemorrhages should also be reported in the “Pulmonary Function” sections on the appropriate Post-Infusion Follow-Up (2100) form.

Stroke should also be reported in the “Other Organ Impairment/Disorder” section on the appropriate Post-Infusion Follow-Up (2100) form.

Hemorrhagic cystitis should also be reported in the “Other Organ Impairment/Disorder” section on the appropriate Post-Infusion Follow-Up (2100) form.

Infection

Report the etiology of the infection as Bacterial, Fungal, Viral, Protozoal, or Other infection, specify. If the organism was not identified, but evidence of infection was present based on clinical opinion, select “Infection, organism not identified.” Also report infections in the “Infection” section on the Post-Infusion Follow-Up (2100) form.

Do not report interstitial pneumonitis (IPn) using this cause of death code. IPn is collected in the “pulmonary” section.

Malignancy

The recipient died with evidence of a new malignancy post-infusion. If the recipient develops a **New malignancy** after transplant, it should also be reported in the “New Malignancy” section on the appropriate Post-Infusion Follow-Up (2100) form.

If there was a *history of malignancy prior to infusion* (i.e., not the primary disease for infusion) and the recipient died with evidence of recurrence, persistence, or progression of the previous malignancy, it should be reported by selecting **Prior malignancy (malignancy initially diagnosed prior to infusion, other than the malignancy for which the infusion was performed).**

Organ failure (not due to GVHD or infection)

If the recipient died with organ failure (not due to GVHD or infection), it should be reported as a cause of death. If the organ system that has failed is not specified, but present at death based on clinical opinion, use **Other organ failure**, and specify the organ involved in question 5 or 7.

Liver failure (not VOD): If a cause of death was liver failure, except for veno-occlusive disease/sinusoidal obstruction syndrome (use VOD/SOS) or GVHD (use Acute GVHD or Chronic GVHD). Liver abnormalities should also be reported in the “Liver Function” sections on the appropriate Post-Infusion Follow-Up (2100) form.

Veno-occlusive disease (VOD) / sinusoidal obstruction syndrome (SOS): If a cause of death was VOD or SOS. Pulmonary veno-occlusive disease should be reported using this cause of death code. Do not report other types of liver failure using this cause of death code. Liver VOD/SOS should also be reported in the “Liver Function” sections of the appropriate Post-Infusion Follow-Up (2100) form.

Cardiac failure: If a cause of death was cardiac failure. Congestive heart failure and myocardial infarctions should also be reported in the ‘Cardiac’ section of the appropriate Post-Infusion Follow-Up (2100).

Pulmonary failure: If a cause of death was pulmonary failure from non-infectious causes such as bronchiolitis obliterans (BO) or cryptogenic organizing pneumonia (COP). BO and COP should also be reported in the “Pulmonary Function” section of the appropriate Post-Infusion Follow-Up (2100) form.

Do not report pulmonary hemorrhage using this cause of death (use **Pulmonary hemorrhage** option).

Central nervous system (CNS) failure: If a cause of death was due to central nervous system failure. CNS failure may include radiation-induced atrophy, brain stem dysfunction, or encephalitis of unknown origin.

- Do not report death due to brain infection (e.g., meningitis) using this cause of death code (Use **Infection**).
- Do not report hemorrhagic stroke using this cause of death code (use **Intracranial hemorrhage**).

Renal failure: If a cause of death was due to renal failure. Renal failure that was severe enough to warrant dialysis (or the recommendation of dialysis) should also be reported on the appropriate Post-Infusion Follow-Up (2100) form.

Gastrointestinal (GI) failure (not liver): If the cause of death was due to gastrointestinal failure (such as intestinal obstruction or perforation).

- Do not report gastrointestinal hemorrhage using this cause of death code (use gastrointestinal hemorrhage).
- Do not report liver failure using this cause of death code (use Liver failure (not VOD)).
- Do not report graft-versus-host disease (GVHD) using this cause of death code (use Acute GVHD or Chronic GVHD).

Multiple organ failure: If the cause of death is due to failure of more than one organ, provide additional detail and specify in question. Do not select this option if there is a root cause of the multiple organ failure (i.e., infection).

If multiple organ failure was due to sepsis, report the **Infection** as a cause of death. The infectious organism should be also reported in the “Infection” section of the Post-Infusion Follow-Up (2100) form.

Other organ failure: If a cause of death was not due to a specific organ or organ system listed above. Specify the organ or organ system involved.

Pulmonary

Adult Respiratory Distress Syndrome (ARDS) (other than IPS): also called acute respiratory distress syndrome, has acute onset, infiltrative respiratory distress. It is considered to be adult respiratory distress syndrome, rather than IPS/IPn. Also report adult respiratory distress syndrome in the “Pulmonary Function” section on the appropriate Post-Infusion Follow-Up (2100) form.

Diffuse alveolar damage (without hemorrhage): describes histological changes found in lung disease. It’s associated with acute respiratory distress syndrome (ARDS) and transfusion related acute lung injury

(TRALI).

Idiopathic pneumonia syndrome (IPS) describes non-infectious lung injuries that occur early after infusion (within 100-120 days). Also report idiopathic pneumonia syndrome in the “Pulmonary Function” section on the appropriate Post-Infusion Follow-Up (2100) form.

Pneumonitis due to Cytomegalovirus (CMV): Pneumonitis can result from infection by cytomegalovirus, adenovirus, respiratory syncytial virus, influenza, or Pneumocystis jirovecii (PCP). Select this option if interstitial pneumonitis resulted from cytomegalovirus. Also report interstitial pneumonitis in the “Pulmonary Function” section on the appropriate Post-Infusion Follow-Up (2100) form.

Pneumonitis due to other virus: Pneumonitis can also result from infection by, adenovirus, respiratory syncytial virus, influenza, or Pneumocystis jirovecii (PCP). Select this option if pneumonitis was caused by a virus. Also report interstitial pneumonitis in the “Pulmonary Function” section on the appropriate Post-Infusion Follow-Up (2100) form

Other pulmonary syndrome (excluding pulmonary hemorrhage): Select this option to report any other pulmonary syndrome, excluding pulmonary hemorrhage. Additionally, select this option for pneumonitis due to any other organism and specify IPn and the organism in question 5 or 7. Also report interstitial pneumonitis in the “Pulmonary Function” section on the appropriate Post-Infusion Follow-Up (2100) form

Toxicity

Neurotoxicity (ICANS): is the development of different neurologic signs and symptoms reported after the infusion of genetically modified lymphocytes.

Tumor lysis syndrome: disorder characterized by metabolic abnormalities that result from a spontaneous or therapy-related cytolysis of tumor cells.

Vascular

If the recipient died with evidence of vascular dysfunction, use the cause of death options to report the specific disorder. If the vascular disorder does not have a cause of death code, use **Other vascular** and report the vascular abnormality.

> ! **Sepsis and Septic Shock**: Sepsis and septic shock should not be reported in the “other” data field as the true cause of death is an infection and should be reported as Infection

Other

Accidental death: The recipient’s death was caused by accidental or unintentional means.

Suicide: The recipient intentionally caused their own death.

In states where physician-assisted suicide is used to hasten death in terminally ill recipients, the cause of

death should be reported as the underlying condition (primary cause of death) and suicide as a contributing cause of death.

Other cause: If the recipient has a cause of death that is not captured using any of the above categories, provide detailed information on the cause of death in question 5 or 7.

Section Updates:

Question Number	Date of Change	Add/Remove/Modify	Description	Reasoning (If applicable)
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