

2900: Recipient Death

The Recipient Death Data (Form 2900) captures cause of death data fields for recipients on the *Comprehensive Report Form* follow-up track. 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 evolves, reporting accurate cause of death data is important to investigating the variables that are associated with post-transplant outcomes.

If “dead” is reported as the current survival status at the date of last contact on the Post-HCT Data (Form 2100) at the 100 day, six month and yearly time points, complete the Recipient Death Data (Form 2900) as soon as possible after the recipient has died.



Do not complete the Recipient Death Data (Form 2900) for:

- **Recipients on the TED track.** Death data is reported on the Post-TED form. Review the Post-TED Manual section for additional instructions for completing cause of death data fields on the Post-TED forms.
- **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 contacting your CRC to open a form for completion. For example, a center may only become aware of the death after it has reported that the recipient is lost to follow-up. 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 reported for the two-year time point, your CRC should be contacted to make the two-year follow-up form due.

[Q1-4: 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
1/31/ 2017	2900: Recipient Death	Modify	Version 2 of the 2900: Recipient Death section of the Forms Instruction Manual released. Version 2 corresponds to revision 3 of the Form 2900.

Q1-4: Recipient Death Data

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 Form 2100.

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 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 “yes,” continue with question 3.
- If “autopsy pending,” continue with question 4. Report the cause of death as determined by a physician. A second Form 2900 will become due six months from the date of death to report any additional cause of death information found during autopsy. All pertinent causes of death should be reported on the second Form 2900.
- If “no,” continue with question 4.
- If “unknown,” continue with question 4.

Question 3: Is an autopsy report attached?

Indicate if a copy of the autopsy report is attached. Use the “Add Attachment” feature to attach a copy of the autopsy report in FormsNet. Attaching a copy of the report may prevent additional queries.

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 (Question 5) 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 5) 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.

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-HCT Data Form.

Chronic GVHD

If reported as a primary or contributing cause of death, chronic GVHD should also be reported on the appropriate Post-HCT Data 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 syndrome (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."

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 2100 form.

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

Pulmonary

Idiopathic pneumonia syndrome (IPS) describes **non-infectious** lung injuries that occur early after HCT (within 100-120 days). Also report idiopathic pneumonia syndrome in the "Pulmonary Function" section on the 2100 form.

Interstitial pneumonitis (IPn) can result from infection by cytomegalovirus, adenovirus, respiratory syncytial virus, influenza, or *Pneumocystis jirovecii* (PCP). Interstitial pneumonitis resulting from cytomegalovirus should be reported using "pneumonitis due to cytomegalovirus." Pneumonitis caused by other virii should be reported as "pneumonitis due to other virus." Pneumonitis due to any other organism can be reported as "other pulmonary syndrome (excluding pulmonary hemorrhage)" and specifying IPn and the virus in question 5 or 7. Also report interstitial pneumonitis in the "Pulmonary Function" section on the appropriate Post-HCT Data 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).

Adult Respiratory Distress Syndrome (ARDS), 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-HCT Data Form.

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. 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 of the appropriate Post-HCT Data 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-HCT Data Form.

Cardiac. If a cause of death was cardiac failure. Congestive heart failure and myocardial infarctions should also be reported on the appropriate Post-HCT Data Form.

Pulmonary. 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-HCT Data Form.

Do not report pulmonary hemorrhage using this cause of death code (use “Pulmonary hemorrhage”).

Central nervous system (CNS). 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. 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-HCT Data Form.

Gastrointestinal (GI) (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, specify. If the cause of death is due to failure of more than one organ, please provide additional detail. Each failed organ system should be reported in the “specify” field (question 5 or 7).

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 2100 form.

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

Malignancy

The recipient died with evidence of a new malignancy post-HCT. If the recipient develops a new malignancy after transplant, it should also be reported in the “New Malignancy” section of the appropriate Post-HCT Data Form.

If there was a history of malignancy prior to transplant (i.e., not the primary disease for which the recipient was transplanted) 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 HCT or cellular therapy, other than the malignancy for which the HCT or cellular therapy was performed).”

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, specify.” and report the organ or location of the hemorrhage.

Pulmonary hemorrhages should also be reported in the “Pulmonary Function” sections on the appropriate Post-HCT Data Form.

Stroke should also be reported in the “Other Organ Impairment/Disorder” section on the appropriate Post-HCT Data Form.

Hemorrhagic cystitis should also be reported in the “Other Organ Impairment/Disorder” section on the appropriate Post-HCT Data Form.

Vascular

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

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 and suicide as a contributing cause of death.

Other cause, specify. If the recipient has a cause of death that is not captured using any of the above categories, please provide detailed information on the cause of death.