2900: Recipient Death (Revision 2)

The Recipient Death Data (Form 2900) captures cause of death data fields for recipients on the *Comprehensive Report Form* follow-up track.

If “dead” is reported as the current survival status at the date of last contact on the 100 Day Post-HCT Data (Form 2100), Six Month to Two Year Post-HCT Data (Form 2200), or the Greater Than Two Years Post-HCT Data (Form 2300), a Recipient Death Data (Form 2900) must be completed to document the primary and contributing cause(s) of death.

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 questions 62-74 of the Post-TED form (revision 2). Please 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.**

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.

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.

Date	Manual Section	Add/Remove/ Modify	Description
6/12/ 15	Manual-wide	Modify	Language relating to the Lost-to-Follow-Up (2802) has been removed.

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, 2200, or 2300.

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, 2200, or 2300, 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.

If an autopsy was performed, review the causes of death listed in the report. In addition, review the status of the disease for which the transplant was performed. Any additional findings from the autopsy about what contributed to death should be reported as the primary cause of death or a contributing cause of death. For example, if evidence of primary disease for transplant wasn’t previously detected, but was found during the autopsy, “**70** Recurrence/persistence/progression of disease reported for first HCT” should be reported as **a** cause of death (not necessarily as the primary cause of death).

Question 3: Is an autopsy report attached?

Indicate if a copy of the autopsy report is attached. Use the Log of Appended Documents (Form 2800) to attach a copy of the autopsy report. Attaching a copy of the report may prevent additional queries.

Question 4: Cause of death:

Primary. 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. If it is necessary to use an “other, specify” field, specify only one “other” primary cause of death. “Other, specify” fields include codes **29, 39, 89, 109, 129,** and **900** and **require** further information. Information reported in the specify fields must pertain to the code selected (e.g., an infectious cause of death should be specified for “**29** Other infection, specify”).

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. One should not assume that the presence of disease indicates that the disease was the primary cause of death.

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

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

Report only one cause of death in each row. If it is necessary to use an “other, specify” field, specify only one “other” cause of death. “Other, specify” fields include codes **29, 39, 89, 109, 129,** and **900** and **require** further information. Information reported in the specify fields must pertain to the code selected (e.g., an infectious cause of death should be specified for “**29** Other infection, specify”).

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.

Cause of Death Codes

10 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.

20-29 Infection (other than idiopathic pneumonia syndrome (IPS)).

✻ Currently there is an error on the paper version Form 2900. The heading of this section on the form should read "**Infection (other than interstitial pneumonitis (IPn)**" rather than "Infection (other than idiopathic pneumonia syndrome (IPS))."

Report the etiology of the infection as **21** Bacterial, **22** Fungal, **23** Viral, **24** Protozoal, or **29** Other infection, specify. If the organism was not identified, but evidence of infection was present based on clinical opinion, select "**20** Organism not identified." Also report infections in the "Infection" section on the 2100 or 2200 form.

Do not report interstitial pneumonitis using this cause of death code.

30-39 Idiopathic pneumonia syndrome (IPS) / interstitial pneumonitis (IPn).

✻ **Idiopathic Pneumonia Syndrome (IPS) / IPn**
Currently there is an error on the Form 2900 regarding idiopathic pneumonia syndrome (IPS) and interstitial pneumonitis (IPn). The cause of death codes should read:
Idiopathic pneumonia syndrome (IPS) / IPn
30 IPS, idiopathic
31 IPn, cytomegalovirus (CMV)
32 IPn, viral, other
39 Other **IPn**, specify

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 or 2200 form.

Interstitial pneumonitis (IPn) can result from infection by cytomegalovirus, adenovirus, respiratory syncytial virus, influenza, or Pneumocystis jirovecii (PCP). Interstitial pneumonitis resulting from Pneumocystis jirovecii (PCP) infection should be reported under "**39** Other IPS [IPn], specify." Also report interstitial

pneumonitis in the “Pulmonary Function” section on the 2100 or 2200 form, or in the “Other Organ Impairment/Disorder” section on the 2300 form.

40 Adult Respiratory Distress Syndrome (ARDS) (other than IPS).

If the recipient 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 2100 or 2200, or the “Other Organ Impairment/Disorder” section on the 2300.

> **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.*

50 Acute GVHD.

If reported as a primary or contributing cause of death, acute GVHD should also be reported on the appropriate follow-up form (Forms 2100, 2200, or 2300).

60 Chronic GVHD.

If reported as a primary or contributing cause of death, chronic GVHD should also be reported on the appropriate follow-up form (Forms 2100, 2200, or 2300).

70 Recurrence / persistence / progression of disease reported for first HCT.

If the disease is present at death, even if it was not the underlying cause of death, “**70** Recurrence/ persistence/progression of disease reported for first HCT” 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).

80-89 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 “**80** Organ failure, not otherwise specified.” If the organ failure does not have a cause of death code, use “**89** Other organ failure, specify,” and report the organ.

80 Organ failure, not otherwise specified. If organ failure was a reported cause of death and the organ system could not be identified.

81 Liver. If a cause of death was liver failure, except for veno-occlusive disease/sinusoidal obstruction syndrome (use **82** VOD/SOS) or GVHD (use **50** Acute GVHD or **60** Chronic GVHD). Liver abnormalities should also be reported in the "Liver Function" sections of the 2100 or 2200 forms, or the "Other Organ Impairment /Disorder" section of the 2300 form.

82 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 2100 or 2200 forms, or the "Other Organ Impairment /Disorder" section of the 2300 form.

83 Cardiac. If a cause of death was cardiac failure. Congestive heart failure and myocardial infarctions should also be reported in the "Other Organ Impairment /Disorder" section of 2100, 2200, or 2300 forms.

84 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 2100 or 2200 forms, or the "Other Organ Impairment/Disorder" section of the 2300 form.

Do not report pulmonary hemorrhage using this cause of death code (use **101** Pulmonary).

85 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 **20-29** Infection).

Do not report hemorrhagic stroke using this cause of death code (use **102** Intracranial).

86 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 in the "Other Organ Impairment /Disorder" section of 2100, 2200, or 2300 forms.

87 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 **103** Gastrointestinal).

Do not report liver failure using this cause of death code (use **81** Liver (not VOD)).

Do not report graft-versus-host disease (GVHD) using this cause of death code (use **50** Acute GVHD or **60** Chronic GVHD).

88 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.

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 or 2200 form.

89 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.

90 Secondary malignancy (new malignancy post-HCT).

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 2100, 2200, or 2300 forms.

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 "**140** Prior malignancy (prior to HCT)."

100-109 Hemorrhage.

If the recipient died with evidence of hemorrhage, use the cause of death codes **100-109** to report its location. If the location of the hemorrhage is not specified, but present at death based on clinical opinion, use "**100** Hemorrhage, not otherwise specified." If the hemorrhage was in an organ system that does not have a cause of death code, use "**109** Other hemorrhage, specify," and report the organ or location of the hemorrhage.

Pulmonary hemorrhages should also be reported in the "Pulmonary Function" sections of the 2100 or 2200 forms, or the "Other Organ Impairment/Disorder" section of the 2300 form.

Stroke should also be reported in the "Other Organ Impairment/Disorder" section of the 2100, 2200, or 2300 forms.

Hemorrhagic cystitis should also be reported in the "Other Organ Impairment/Disorder" section of the 2100, 2200, or 2300 forms.

110 Accidental Death.

The recipient's death was caused by accidental or unintentional means.

115 Suicide.

The recipient intentionally causes 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.

120-129 Vascular.

If the recipient died with evidence of vascular dysfunction, use the cause of death codes **120-129** to report the specific disorders. If a vascular disorder is not specified but present at death based on clinical opinion, use "**120** Vascular, not otherwise specified." If the vascular disorder does not have a cause of death code, use "**129** Other vascular, specify" and report the vascular abnormality.

123 Thrombotic thrombocytopenic purpura (TTP) and hemolytic uremic syndrome (HUS)

Should also be reported in the "Other Organ Impairment/Disorder" section of the 2100, 2200, or 2300 forms.

140 Prior malignancy (prior to HCT, and reported on baseline form at history of malignancy).

If the recipient died with evidence of a malignancy diagnosed prior to transplant (including recurrence, persistence, or progression of the prior malignancy after HCT). For example, a recipient may have a history of breast cancer, but then developed and was transplanted for lymphoma. If the recipient died due to breast cancer, or breast cancer was present upon death, this option should be selected as a primary or contributing cause of death.

If the recipient has a history of prior malignancy, it should also be reported on the Recipient Baseline Data (Form 2000) in the history of malignancy questions (Questions 22-60, revision 2). If the prior malignancy was a solid tumor (excluding non-melanoma skin cancer), it should also be reported on the Pre-TED form (From 2400, question 142, revision 2).

Use "**90** Secondary malignancy (new malignancy post-HCT)," if the recipient developed a new malignancy post-transplant.

900 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.