Post-Transplant Malignancy (PTM) Record Field Descriptions

The Post-Transplant Malignancy (PTM) record is generated after a malignancy has been reported in the Transplant Recipient Follow-up (TRF) record. The record should be completed by the transplant center responsible for the follow-up of the recipient at the time the cancer was reported. If the patient has more than one follow-up record because of a multi-organ transplant, the malignancy only needs to be reported in one of the follow-up records. If it is reported in more than one, only one PTM record will be generated.

If **Yes** was selected for Post Transplant Malignancies, along with one or more of the post transplant malignancies listed on the TRF record, the following sections will display in the Post-Transplant Malignancy record: Donor Related, Recurrence of Pretransplant Malignancy, Post Transplant De Novo Solid Tumor and/or Post Tx Lymphoproliferative Disease and Lymphoma.

To change the section of the malignancy record that was generated, access the TRF record and select **No** to the section that is not needed, and select **Yes** to the section of the malignancy record that is needed. To delete the malignancy record, re-access the TRF record and select **No** in the Post Transplant Malignancies field.

Note: If no information is available about the malignancy except the fact that they were treated, contact the UNet Help Desk at 1-800-978-4334. They will have the PTM record validated.

The PTM must be completed within 30 days from the record generation date. See <u>OPTN/UNOS</u> <u>Policies</u> for additional information. Use the search feature to locate specific policy information on Data Submission Requirements.

To correct information that is already displayed in an electronic record, call the UNOS Help Desk at 1-800-978-4334.

Recipient Information

The following fields reported in the recipient's last completed TRF record display.

Recipient name: Verify the last name, first name and middle initial of the transplant recipient.

Date of birth: Verify the recipient's date of birth.

Recipient SSN: Verify the recipient's social security number.

Recipient organ: Verify the type of organ transplanted.

<u>TRF</u>: Verify the Transplant Recipient Follow-up record number from which this malignancy record was generated.

Follow-up code: Verify the TRF Follow-up Code for the record from which this malignancy record was generated.

<u>Transplant date</u>: Verify that the displayed transplant date is the date of the beginning of the first anastomosis. If the operation started in the evening and the first anastomosis began early the next morning, the transplant date is the date that the first anastomosis began. The transplant is considered complete when the cavity is closed and the final skin stitch/staple is applied.

Follow-up center: Verify that the follow-up center listed is responsible for the follow-up of the recipient at the time the cancer was reported.

<u>Recipient center</u>: Verify that the transplant center listed is where the transplant procedure took place.

Donor Related

This section will only display if Yes was selected for Donor Related on post transplant malignancies listed in the TRF record.

Tumors transmitted from the donor

In most instances the donor does not have a history of cancer and transmission of cancer is unexpected. This occurrence is usually discovered when multiple recipients of organs from a single donor develop the same cancer (e.g. Melanoma). It may also occur when the clinical (not histological) diagnosis of primary brain cancer is made when, in fact, the donor had a metastatic brain cancer from an occult (concealed from observation) primary site.

Diagnosis date: Enter the date of diagnosis using the standard 8-digit format of MM/DD/YYYY. The date must fall within the follow-up period and after the transplant date that is displayed. This field is **required**.

Immunosuppression: Select the status of immunosuppression from the drop-down box. (List of Immunosuppression Status codes)

Immunosuppression Stopped Immunosuppression Reduced No Immunosuppression Adjustment

<u>Type of Tumor</u>: Select the type from the drop-down list. This field is **required**. (<u>List of Tumor Type</u> <u>codes</u>)

Primary to the transplanted organ Not primary to the transplanted organ

Specify treatment: Select the type of treatment used for this type of tumor by clicking on the checkbox beside the treatment type.

Surgical resection tumor

Chemotherapy: Select the type of treatment from the drop-down list. If **Other, specify** is selected, enter the name of the treatment in the **Other specify** field. (List of Chemotherapy codes)

CHOP MACOP-B **Pro-Mace-CytaBOM** M-BACOD 5FU/Gemzar 5FU/Leucovorin 5FU/Leucovorin/CPT-11 5FU/Mitomycin ACDA Adriamycin Anedia Bleomycin/Cisplatin/Etoposide Carboplatin/Etoposide Carboplatin/Taxol/Gemcitabine Carboplatin/VP-16 **Cisplatin/VP-16** Cyclophosphamide Cyclophosphamide/Prednisone Cytoxan Cytoxan/Adriamycin Cytoxan/Onkovin/Adriamycin/Prednisone DHAP Doxorubicin Doxorubicin/and/Streptozocin EPOCH

Etoposide/Doxorubicin/Vincristine Etropralide/Ifosfamide Eulexin/Lupron Gemcitabine Leucovorin/Methotrexate Lupron Melphazan/Prednisone **Methotrexate** Mitomycin/Carboplatin Navelbine/Taxol Nilandron Tamoxifen Taxol/5FU/Carb Taxol/Adriamycin Taxol/Carboplatin Taxol/Carboplatin/Zofran Topotecan Vidarabine/Cisplatin/Dexamethasone Vincristine Vincristine/Prednisone **VP16** VP16/Etoposide Carboplatin/Gemcitabine Other, specify

Radiation

Immunotherapy: Select the type of treatment from the drop-down list. If **Other, specify** is selected, enter the name of the treatment in the **Other specify** field. (List of Immunotherapy codes)

Hormonal Therapy Interferon Alpha Prednisone Rituximab Other, specify

Other Treatment Specify: Enter the name of any other tumor treatment that was given.

Outcome: Select the outcome from the drop-down list. (List of Outcome codes)

Alive, Free of Tumor Alive with Tumor Dead, due to tumor Dead, other causes

Recurrence of Pretransplant Malignancy

This section will only display if Yes was selected for Recurrence of Pretransplant Malignancy on post transplant malignancies listed in the TRF record.

The patient has a past history of cancer, and develops the same type of cancer post-transplantation. This does not apply to basal cell or squamous cell carcinoma of the skin, unless it recurs in the original site. The patient has a cancer in an explanted (removed) organ (usually liver or maybe kidney), and later develops a recurrence of the same type of cancer. For example, the patient has a hepatocellular carcinoma of the native liver (hepatoma), which is resected at the time of transplantation, and develops a recurrent hepatocellular carcinoma (at any site, at any time).

<u>Type of pre-existing tumor</u>: Select type of pre-existing tumor from the drop-down list. This field is required. If **Other Cancer, Specify** is selected, enter the type of pre-existing tumor in the **Other specify** field. (List of Pre-existing Tumor codes)

Skin (Squamous, Basal Cell) Skin - Melanoma **Genitourinary - Bladder Genitourinary - Uterine Cervix** Genitourinary - Uterine Body (endometrial & choriocarcinoma) **Genitourinary - Vulva Genitourinary - Ovarian Genitourinary - Testicular Genitourinary - Prostate Genitourinary - Kidney Gastrointestinal - Stomach Gastrointestinal - Small Intestine Gastrointestinal - Carcinoid Gastrointestinal - Colo-Rectal** Gastrointestinal - Liver/Biliary Tract (incidental time of hepatectomy) Gastrointestinal - Liver/Biliary tract, not incidental **Gastrointestinal - Pancreas** Thyroid Breast Tongue/Mouth,Pharynx Larynx Lung (include bronchial) Leukemia Lymphoma Other Cancer, Specify

If skin # of occurrences in follow-up period: Enter the number of skin tumors during the followup period.

If Colo-rectal, Duke's Classification: Select the Duke's classification from the drop-down list. (List of Duke's Classification codes)

Dukes A - Tumor is limited to the mucosa (Inner lining).
Dukes B - Tumor is limited to the muscularis (muscle wall).
Dukes C - Tumor extends through the bowel wall and has nodal metastasis.
Unknown

If Lymphoma, specify type: Enter the type of lymphoma.

If Leukemia: Select the type of leukemia from the drop-down list. (List of Leukemia codes)

AML (acute myelocytic leukemia) ALL (acute lymphocytic leukemia) MDS (myelodysplasia syndrome) CML (chronic myelocytic leukemia) CLL (chronic lymphocytic leukemia) Other

If other cancer, specify: Enter the type of cancer.

<u>Treatments of pre-existing tumor</u>: Indicate the type of treatment used for the pre-existing tumor by clicking in the checkbox beside the treatment type.

Treatment date: Enter the date of treatment using the standard 8-digit format of MM/DD/YYYY. This date must be before or equal to the transplant date.

Surgery: If surgery was used, select the type of surgery from the drop-down list. If **Other, specify** is selected, enter the type of the surgery in the **Other specify** field. (List of Surgery codes)

Biopsy Resection

Limited Resection; debulking Other, specify

Chemotherapy: Select the type of treatment from the drop-down list. If **Other, specify** is selected, enter the name of the treatment in the **Other specify** field. (List of Chemotherapy codes)

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Radiation

Other treatment specify: Enter the name of any other tumor treatment.

Date of recurrence (post-tx): Enter the date, using the standard 8-digit format of MM/DD/YYYY, the cancer recurred. This date must be after the transplant date and fall within the follow-up period that is displayed. This field is required.

Site(s) affected: Select the site(s) affected by clicking on the checkbox next to the site.

Primary organ Adjacent organs Regional lymph nodes Distant metastases

Immunosuppression: Select the status of the immunosuppression from the drop-down list. (List of Immunosuppression codes)

Immunosuppression Stopped Immunosuppression Reduced No Immunosuppression Adjustment

<u>Treatments of recurrent tumor</u>: Indicate the type of treatment used for the recurrent tumor by clicking in the checkbox beside the treatment type.

Surgery: If surgery was used, select the type of surgery. If Other, specify is selected, enter the name of the surgery in the Other specify field. (List of Surgery codes)

Biopsy Resection Limited Resection; debulking Other, specify

Chemotherapy: Select the type of treatment from the drop-down list. If **Other, specify** is selected, enter the name of the treatment in the **Other specify** field. (List of Chemotherapy codes)

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Radiation

Immunotherapy: Select the type of treatment from the drop-down list. If **Other, specify** is selected, enter the name of the treatment in the **Other specify** field. (List of Immunotherapy codes)

Hormonal Therapy Interferon Alpha Prednisone Rituximab Other, specify

Other treatment specify: Enter the name of any other tumor treatment.

Outcome: Select the outcome from the drop-down list. (List of Outcome codes)

Alive, Free of Tumor Alive with Tumor Dead, due to tumor Dead, other causes

Post Transplant De Novo Solid Tumor

This section will only display if Yes was selected for Post Transplant De Novo Solid Tumor on post transplant malignancies listed in the TRF record.

This includes all new malignant tumors except Post Transplant Lymphoproliferative Disease. This includes all skin cancers, sarcomas, adenocarcinomas, hematological malignancies, and many cancers with special names. It does not include benign tumors such as nevi, adenomas, or fibromas. Usually, the description should include the type of cancer (e.g. squamous cell, adenocarcinoma), and the organ involved.

Select the one or more tumor types: Select all tumor types that apply to the patient by clicking on the checkbox next to the type. This field is **required**.

Skin: If squamous cell, basal cell and/or melanoma skin tumors are selected, complete the following section:

Sites: Select the site(s) affected by clicking on the checkbox next to the site.

Single Multiple

Site Location: Indicate the area by selecting Lips/Head/Neck, Extremities or Trunk.

Spread: Indicate if the skin malignancy has spread by selecting **None**, **Nodes** and/or **Other**. If **Other** is selected, enter the location.

of occurrences: Enter the number of occurrences during the follow-up period. If the number of occurrences during the follow-up period is unavailable, select the reason from the status (**ST**) drop-down list (**Missing**, **Unknown**, **N/A**, **Not Done**).

Kaposi's sarcoma: cutaneous

Kaposi's sarcoma: visceral

Brain: Select the specific type of brain tumor from the drop-down list. If **Other Specify** is selected, enter the type of tumor in the **Other specify** field. (List of Brain Tumor codes)

Astrocytoma Medulloblastoma Glioblastoma Multiforme Neuroblastoma Meningioma, Malignant Meningioma, Benign Angioblastoma Other Specify

Renal carcinoma - Specify Site(s): Enter the site(s) in the space provided.

Carcinoma of vulva, perineum or penis, scrotum

Carcinoma of uterus: Select the type of carcinoma from the drop-down list. (<u>List of Uterine</u> Carcinoma codes)

Cervix, invasive Cervix, in situ Body, Endometrium

Ovarian

Testicular

Esophagus

Stomach

Small intestine

Pancreas

Larynx

Tongue, throat

Thyroid

Bladder

Breast

Prostate

Colo-rectal, Duke's Classification: Select the Duke's classification from the drop-down list. (List of Duke's Classification codes)

Dukes A - Tumor is limited to the mucosa (inner lining) **Dukes B** - Tumor is limited to the muscularis (muscle wall) **Dukes C** - Tumor extends through the bowel wall and has nodal metastasis. **Unknown**

Primary Hepatic Tumor: Select the type of tumor from the drop-down list. If **Other** is selected, specify the name in the **Other specify** field. (List of Hepatic Tumor codes)

Hepatocellular Carcinoma Cholangiocarcinoma Epithelioid-Hemangio-Endothelioma Hepatoblastoma Hemangiosarcoma Other

Metastatic Liver Tumor - Specify Original Site: Select the original site from the drop-down list. If Other is selected, enter the site in the Other specify field. (List of Metastatic Liver Tumor codes)

Stomach Adenocarcinoma Colon Adenocarrcinoma Breast Carcinoma Pancreas Carcinoma Bronchial Carcinoma Carcinoid (Neuroendocrine) Other

Lung (include bronchial): Indicate either Small Cell or Non-small Cell.

Leukemia: Select the leukemia type from the drop-down list. (List of Leukemia codes)

AML (acute myelocytic leukemia) ALL (acute lymphocytic leukemia) MDS (myelodysplasia syndrome) CML (chronic myelocytic leukemia) CLL (chronic lymphocytic leukemia) Other

Sarcomas (excluding Kaposi's)

Site(s): Enter the site(s).

Specify type: Select the type of sarcoma from the drop-down list. If **Other** is selected, enter the type in the **Other specify** field. (<u>List of Sarcoma codes</u>)

Fibrosarcoma Liposarcoma Leiomyosarcoma Rhabdomyosarcoma Angiosarcoma Malignant Hemangiopericytoma Neurofibrosarcoma Neuroblastoma Chondrosarcoma Osteosarcoma Ewing's sarcoma Other

If **Other Cancers** is selected, enter the **Site(s)** and the type of cancer in the spaces provided (this field is **required**).

Primary Unknown: Select if the type of tumor is unknown.

Outcome: Select the outcome from the drop-down list. (List of Outcome codes)

Alive, Free of Tumor Alive with Tumor Dead, due to tumor Dead, other causes

The Treatment Information must be completed when a type of tumor is selected from the Post Transplant De Novo Solid Tumor section of the record. All applicable fields must be completed.

Site(s) affected: Select affected site(s).

Primary organ Adjacent organs Regional lymph nodes Distant metastases

Diagnosis date: Enter the date using the standard 8-digit format of MM/DD/YYYY. The date must fall within the follow-up period and after the transplant date that is displayed.

Immunosuppression: Select the status of immunosuppression from the drop-down box. (List of Immunosuppression codes)

Immunosuppression Stopped Immunosuppression Reduced No Immunosuppression Adjustment

Specify treatment: Select the type of treatment used for this type of tumor by clicking on the checkbox beside the treatment type.

Surgery: If surgery was used, select the type of surgery. If **Other specify** is selected, enter the type of the surgery in the space provided (this field is **required**). (List of Surgery codes)

Biopsy Resection Limited Resection; debulking Other, specify

Cryotherapy (skin cancer): Indicate if cryotherapy was used.

Chemotherapy: Select the type of treatment from the drop-down list. If **Other, specify** is selected, enter the name of the treatment in the **Other specify** field (this field is **required**). (<u>List of</u> <u>Chemotherapy codes</u>)

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Cytoxan/Onkovin/Adriamycin/Prednisone DHAP Doxorubicin Doxorubicin/and/Streptozocin EPOCH Etoposide/Doxorubicin/Vincristine Etropralide/Ifosfamide Eulexin/Lupron Gemcitabine Leucovorin/Methotrexate Lupron Melphazan/Prednisone **Methotrexate** Mitomycin/Carboplatin Navelbine/Taxol Nilandron Tamoxifen Taxol/5FU/Carb Taxol/Adriamycin Taxol/Carboplatin Taxol/Carboplatin/Zofran Topotecan Vidarabine/Cisplatin/Dexamethasone Vincristine Vincristine/Prednisone **VP16** VP16/Etoposide Carboplatin/Gemcitabine Other, specify

Immunotherapy: Select the type of treatment from the drop-down list. If **Other, specify** is selected, enter the name of the treatment in the **Other specify** field (this field is **required**). (List of Immunotherapy codes)

Hormonal Therapy Interferon Alpha Prednisone Rituximab Other, specify

Radiation: Indicate if radiation was used.

Other treatment: Enter the name of any other tumor treatment.

Best treatment response: Select the best treatment response.

Progressive Disease (PD) Partial Response (PR) No Treatment (NT) Too Early in Treatment to Evaluate (TE) Stable Disease (SD) Complete Response (CR)

Post Transplant Lymphoproliferative Disease and Lymphoma

This section will only display if Yes was selected for Post TX Lymphoproliferative Disease and Lymphoma on post transplant malignancies listed in the TRF record.

Lymphoid growths that occur in organ transplant patients, in which evidence of Epstein-Barr virus (EBV) can be demonstrated; a family of lesions that straddle the border between infection and neoplasia (tumors). The spectrum runs from infectious mononucleosis to clonal proliferation of lymphoid cells to gross tumor formation and malignancy. PTLDs must be distinguished from sporadic lymphomas or non-EBV-associated lymphadenopathies, which may also be seen in the transplant population.

Diagnosis date: Enter the date using the standard 8-digit format of MM/DD/YYYY. The date must fall within the follow-up period and after the transplant. This field is **required**.

<u>Pathology</u>: Select the pathology of the disease from the drop-down list. This field is **required**. If **Other**, **Specify** is selected, enter the disease in the **Other Specify** field. (<u>List of Pathology codes</u>)

Polymorphic Hyperplasia Polymorphic PTLD(lymphoma) Monomorphic PTLD(lymphoma) Multiple Myeloma, Plasmacytoma Hodgkin's Disease Other, Specify

Clonality: Select the clonality of the disease from the drop-down list. (List of Clonality codes)

Monoclonal Polyclonal Oligoclonal Unknown

<u>Predominant cell type</u>: Select the predominant cell type from the drop-down list. If **Other, specify** is selected, enter the name in the **Other specify** field. (List of Predominant Cell Type codes)

B Cell T Cell Other Specify Unknown

Epstein-Barr virus (EBV) status of tumor: Select the result by clicking on the circle next to the result.

EBV positive EBV negative Unknown

Anatomy: Select the site type by clicking on the circle next to the anatomy site.

Single Site Multiple Sites

Lymph nodes: If lymph nodes are affected, select Yes. If not, select No.

If extranodal sites are applicable (sites outside of the lymph nodes), select the site(s) by clicking on the checkbox next to the type.

Stomach Small Intestine Colon Allograft Lung Bone Marrow CNS Liver

Other specify: Enter any other sites.

<u>Ann ArborStage</u>: Ann Arbor is a classification of Non-Hodgkin's Lymphomas. Indicate if the Ann Arbor stage is I, II, III, or IV. If unknown, select **Unknown**

Stage I - Involvement of a single lymph node group or a single extralymphatic organ or site.

Stage II - Involvement of two or more lymph node regions on the same side of diaphragm alone or with localized involvement of an extralymphatic organ or site (on the same side of the diaphragm).

Stage III- Involvement of lymph node regions on both sides of the diaphragm alone or with localized involvement of an extralymphatic organ or site, or spleen, or both (on both sides of the diaphragm).

Stage IV - Diffuse or disseminated involvement of one or more extralymphatic organs with or without associated lymph node involvement.

PTLD Treatment:

Abbreviations:

- **PD** Progressive Disease
- **SD** -Stable Disease
- **PR** Partial Response
- **CR** Complete Response
- TE Too Early in Treatment to Evaluate
- 1. Reduction/Cessation of immunosuppression: If immunosuppression has been reduced or discontinued, select Yes. If the immunosuppression remains unchanged, select No.

If yes, **Best response:** Select the best response to treatment by clicking on the checkbox next to the abbreviation.

PD SD PR CR TE

2. Surgery Type: Select the type of surgery from the drop-down list. If Other, specify is selected, enter the type in the Other specify field. (List of Surgery Type codes)

Biopsy Resection Limited Resection; debulking No Surgery Other, specify

If yes, **Best response:** Select the best response to treatment by clicking on the checkbox next to the abbreviation.

PD SD PR CR TE

3. Anti-viral therapy: If anti-viral therapy was used, select Yes. If not, select No. (List of Antiviral Therapy codes)

If yes, select **Drug 1** from the drop-down list. If **Other, specify** is selected, enter the drug in the **Other specify** field. If a second drug was used, select the drug from the **Drug 2** drop-down list. If a second drug was not used, leave the **Drug 2** field blank.

Acyclovir Cytogam Cytovene Foscarnet Ganciclovir IVIG Valtrex Other, specify

Best response: Select the best response to treatment by clicking on the checkbox.

- PD SD PR CR
- ΤE
- 4. Chemotherapy: If chemotherapy was used, select Yes. If not, select No.

If yes, select **Drug/Regimen 1** from the drop-down list. If **Other, specify** is selected, enter the drug in the **Other specify** field. If a second drug was used, select the drug from the **Drug/Regimen 2** from the drop-down list. If a second drug was not used, leave the **Drug/Regimen 2** field blank. (List of Chemotherapy codes)

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Taxol/Carboplatin Taxol/Carboplatin/Zofran Topotecan Vidarabine/Cisplatin/Dexamethasone Vincristine Vincristine/Prednisone VP16 VP16/Etoposide Carboplatin/Gemcitabine Other, specify

If yes, **Best response:** Select the best response to treatment by clicking on the checkbox.

PD SD PR CR TE

5. Radiation Therapy: If radiation therapy was used, select Yes. If not, select No.

If yes, **Best response:** Select the best response to treatment by clicking on the checkbox next to the abbreviation.

PD SD PR CR TE

6. Immunotherapy: If chemotherapy was used, select Yes. If not, select No.

If **Yes** is selected, select the type of immunotherapy from the drop-down list. If **Other**, **specify** is selected, enter the name of the treatment in the **Other**, **specify** field. (<u>List of</u> <u>Immunotherapy codes</u>)

Hormonal Therapy Interferon Alpha Prednisone Rituximab Other, specify

Best response: Select the best response to treatment by clicking on the checkbox.

PD SD PR CR TE