

Tissue Source Site (TSS) Name: _____ TSS Identifier: _____ TSS Unique Patient #: _____

Completed By: _____ Completion Date (MM/DD/YYYY): _____

Form Notes: A Follow-up Form is to be completed 12 months after a case is shipped to the Biospecimen Core Resource (BCR) for cases that have qualified. All information provided on this form includes activity from the "Date of Last Contact" provided on the TCGA Enrollment Form to the most recent date of contact with the patient. This form should only be completed by the Tissue Source Site if updated information can be provided to TCGA. Questions regarding this form should be directed to the Tissue Source Site's (TSS) primary Clinical Outreach Contact at the BCR.

The following definitions for the use of "Unknown" and "Not Evaluated" on this form are as follows:

Unknown: This answer option should only be selected if the TSS cannot answer the question because the answer is not known at the TSS. If this answer option is selected for a question that is part of the TCGA required data set, the TSS must complete a discrepancy note providing the reason why the answer is unknown.

Not Evaluated: This answer option should be selected by the TSS if it is known that the information being requested cannot be obtained due to the test not being performed.

Question#	Data Element Label	Data Entry Alternatives	CDE ID With Working Instructions
1	Has this TSS received permission from NCI to provide time intervals as a substitute for requested dates on this form?	<input type="checkbox"/> Yes <input type="checkbox"/> No	Please note that time intervals must be recorded in place of dates where designated throughout this form if you have selected "yes" in the box to the left. Note 1: Provided time intervals must begin with the date of initial pathologic diagnosis. (i.e., biopsy or resection) Note 2: Only provide interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.
2	Reason For Follow-up Form Submission	<input type="checkbox"/> Scheduled (Routine) Follow-up Submission <input type="checkbox"/> Additional New Tumor Event	3233305 Indicate the reason for submission of this follow-up form. If scheduled follow-up, complete entire form. If additional new tumor event, complete only questions pertaining to new tumor.
3	Is This Patient Lost to Follow-up?	<input type="checkbox"/> Yes <input type="checkbox"/> No	61333 Indicate whether the patient is lost to follow-up as defined by the ACoS Commission on Cancer. This only includes cases where updated information has not been collected within the last 15 months. If the patient is lost to follow-up, the remaining questions may be left unanswered. Note: If the patient is deceased and a TCGA Follow-up Form has not yet been completed, the answer to this question should be "No" and the remaining applicable questions should be completed.
4	Adjuvant (Initial) Radiation Therapy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	2005312 Indicate whether the patient had adjuvant (initial) Post-operative radiation therapy. Note: If the patient did have adjuvant (initial) radiation, the Radiation Supplemental Form should be completed.
5	Adjuvant (Initial) Pharmaceutical (Systemic) Therapy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	3397567 Indicate whether the patient had adjuvant (initial) / post-operative pharmaceutical therapy. Note: If the patient did have adjuvant pharmaceutical therapy, the Pharmaceutical Supplemental Form should be completed
6	Measure of Success of Outcome at the Completion of Initial First Course Treatment	<input type="checkbox"/> CR (Complete Remission/Response) <input type="checkbox"/> PD (Progressive Disease) <input type="checkbox"/> PR (Partial Remission/Response) <input type="checkbox"/> Not Applicable <input type="checkbox"/> SD (Stable Disease) <input type="checkbox"/> Unknown	2786727 Provide the patient's response to their initial first course of treatment. Note: For lymphoma patients, success of outcome should be determined according to the Cheson Criteria.
7	PET Scan Results (Performed within 2 Months After Completion of Treatment)	<input type="checkbox"/> Positive <input type="checkbox"/> Indeterminate <input type="checkbox"/> Negative <input type="checkbox"/> Not Done	2603749 Provide the results of the PET Scan which was performed to identify the absence or presence of disease within two months after the completion of the first course of treatment.
8	Vital Status	<input type="checkbox"/> Living <input type="checkbox"/> Deceased	5 Indicate whether the patient was living or deceased at the date of last contact.

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Date of Last Contact			
9	Month of Last Contact	<input type="text"/> <input type="text"/> (MM)	2897020 If the patient is living, provide the month of last contact with the patient (as reported by the patient, medical provider, family member, or caregiver). Note: Do not answer this question if the patient is deceased.
10	Day of Last Contact	<input type="text"/> <input type="text"/> (DD)	2897022 If the patient is living, provide the day of last contact with the patient (as reported by the patient, medical provider, family member, or caregiver). Note: Do not answer this question if the patient is deceased.
11	Year of Last Contact	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> (YYYY)	2897024 If the patient is living, provide the year of last contact with the patient (as reported by the patient, medical provider, family member, or caregiver). Note: Do not answer this question if the patient is deceased.
12	Number of Days from Date of Initial Pathologic Diagnosis to Date of Last Contact	_____	3008273 Provide the number of days from the date the patient was initially diagnosed pathologically with the disease to the date of last contact. Note: Only provide Interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.
Date of Death <input type="checkbox"/> Not Applicable (Patient is Alive)			
13	Month of Death	<input type="text"/> <input type="text"/> (MM)	2897026 If the patient is deceased, provide the month of death.
14	Day of Death	<input type="text"/> <input type="text"/> (DD)	2897028 If the patient is deceased, provide the day of death.
15	Year of Death	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> (YYYY)	2897030 If the patient is deceased, provide the year of death.
16	Number of Days from Date of Initial Pathologic Diagnosis to Date of Death	_____	3165475 Provide the number of days from the date the patient was initially diagnosed pathologically with the disease to the date of Death. Note: Only provide Interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.
17	Tumor Status	<input type="checkbox"/> Tumor Free <input type="checkbox"/> With Tumor <input type="checkbox"/> Unknown Tumor Status	2759550 Indicate whether the patient was tumor/disease free from the tumor submitted for TCGA at the date of last contact or death.
Please verify that new tumor event information has not previously been reported on the Enrollment Form or on a prior Follow-up Form			
18	New Tumor Event After Initial Treatment? (First Tumor Progression After Initial Treatment?)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	3121376 Indicate whether the patient had a new tumor event (e.g. metastatic, recurrent, or new primary tumor) after their initial treatment for the tumor submitted to TCGA. If the patient had multiple new tumor events, a follow-up form should be completed for each new tumor event.
Date of New Tumor Event After Initial Treatment (Date of First Tumor Progression After Initial Treatment)			
19	Month of New Tumor Event After Initial Treatment	<input type="text"/> <input type="text"/> (MM)	3104044 If the patient had a new tumor event, provide the month of diagnosis for this new tumor event.
20	Day of New Tumor Event After Initial Treatment	<input type="text"/> <input type="text"/> (DD)	3104042 If the patient had a new tumor event, provide the day of diagnosis for this new tumor event.
21	Year of New Tumor Event After Initial Treatment	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> (YYYY)	3104046 If the patient had a new tumor event, provide the year of diagnosis for this new tumor event.

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Question#	Data Element Label	Data Entry Alternatives	CDE ID With Working Instructions
22	Number of Days from Date of Initial Pathologic Diagnosis to Date of New Tumor Event	_____	3392464 Provide the number of days from the date the patient was initially diagnosed pathologically with the disease to the date of new tumor event. Note: Only provide Interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.
23	Site of First Malignant Lymphoma Progression	Nodal <input type="checkbox"/> Axillary <input type="checkbox"/> Iliac-external <input type="checkbox"/> Parotid <input type="checkbox"/> Cervical <input type="checkbox"/> Inguinal <input type="checkbox"/> Popliteal <input type="checkbox"/> Epitrochlear <input type="checkbox"/> Mediastinal <input type="checkbox"/> Retroperitoneal <input type="checkbox"/> Femoral <input type="checkbox"/> Mesenteric <input type="checkbox"/> Splenic <input type="checkbox"/> Hilar <input type="checkbox"/> Occipital <input type="checkbox"/> Supraclavicular <input type="checkbox"/> Iliac- common <input type="checkbox"/> Paraaortic <input type="checkbox"/> Submandibular <input type="checkbox"/> Lymph Nodes – NOS (Not Otherwise Specified) Extranodal <input type="checkbox"/> Adrenal <input type="checkbox"/> Bone marrow <input type="checkbox"/> Peripheral blood <input type="checkbox"/> Bone <input type="checkbox"/> Breast <input type="checkbox"/> Skin <input type="checkbox"/> Soft Tissue(Muscle,Ligaments,Subcutaneous) Central Nervous System <input type="checkbox"/> Brain <input type="checkbox"/> Epidural <input type="checkbox"/> Leptomeninges ENT & Eye <input type="checkbox"/> Intraocular <input type="checkbox"/> Oropharynx <input type="checkbox"/> Salivary Gland <input type="checkbox"/> Larynx <input type="checkbox"/> Parotid Gland <input type="checkbox"/> Sinus <input type="checkbox"/> Nasal Soft Tissue <input type="checkbox"/> Peri-orbital <input type="checkbox"/> Thyroid <input type="checkbox"/> Nasopharynx <input type="checkbox"/> Soft Tissue Gastrointestinal / Abdominal <input type="checkbox"/> Ascites/Peritoneum <input type="checkbox"/> Stomach <input type="checkbox"/> Liver <input type="checkbox"/> Appendix <input type="checkbox"/> Gallbladder <input type="checkbox"/> Pancreas <input type="checkbox"/> Colon <input type="checkbox"/> Small Intestines <input type="checkbox"/> Rectum <input type="checkbox"/> Esophagus Genito-urinary Tract <input type="checkbox"/> Epididymis <input type="checkbox"/> Ovary <input type="checkbox"/> Testes <input type="checkbox"/> Kidney <input type="checkbox"/> Prostate <input type="checkbox"/> Uterus Mediastinal / Intra-thoracic <input type="checkbox"/> Heart <input type="checkbox"/> Mediastinal Soft Tissue <input type="checkbox"/> Pericardium <input type="checkbox"/> Lung <input type="checkbox"/> Pleura / Pleural Effusion <input type="checkbox"/> Other (Please specify)	3282650 Provide the anatomic location (lymphatic or extralymphatic) of the site of first malignant lymphoma progression.
24	Other Specified Extranodal Site of First Malignant Lymphoma Progression	_____	3282651 If the extranodal site of first malignant lymphoma progression is not included in the provided list, specify the other anatomic location for the first malignant lymphoma progression.
25	Was Site of First Progression Biopsied?	<input type="checkbox"/> Yes <input type="checkbox"/> No	2716366 If the patient has had progression of disease, indicate whether the site of first progression was biopsied.
26	If Site of First Malignant Lymphoma Progression was Biopsied, What was the Histologic Type?	<input type="checkbox"/> DLBCL <input type="checkbox"/> Other Histologic Type (please specify below)	3282652 Indicate the histologic diagnosis (type) of the tissue biopsied for the first progression of the malignant lymphoma.

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27	If Site of First Malignant Lymphoma Progression was Biopsied, Other Specified Histologic Type?	_____	3282653 If the first site of malignant lymphoma progression is not DLBCL, specify the other histologic diagnosis (type) of the tissue biopsied for the first progression of the malignant lymphoma.
28	Measure of Success of Outcome at the Completion of This Follow-up Submission	<input type="checkbox"/> CR (Complete Remission/Response) <input type="checkbox"/> PD (Progressive Disease) <input type="checkbox"/> PR (Partial Remission/Response) <input type="checkbox"/> Not Applicable <input type="checkbox"/> SD (Stable Disease) <input type="checkbox"/> Unknown	3104050 Provide the patient's outcome of treatment up to the point of the current follow-up data submission. Note: For lymphoma patients, success of outcome should be determined according to the Cheson Criteria.

Comments:

Principal Investigator Name: _____ Principal Investigator Signature: _____

Date Signed (MM/DD/YYYY): _____