

Enrollment Form

Burkitt Lymphoma Genome Sequencing Project (BLGSP)

Instructions: The Clinical Data needed to complete this Enrollment Form should be collected for each patient in the Burkitt Lymphoma Genome Sequencing Project (BLGSP) prior to acquisition of tissues. Upon qualification notice from the Office of Cancer Genomics (OCG), the Tissue Source Site (TSS) should complete this Enrollment form for each qualified case within 60 days.

Questions regarding this form should be directed to the Nationwide Children's Hospital (NCH) or OCG.

Please note the following definitions for the "Unknown" and "Not Evaluated" answer options on this form.

Unknown: This answer option should only be selected if the TSS does not know this information after all efforts to obtain the data have been exhausted. If this answer option is selected for a question that is part of the BLGSP required data set, the TSS must complete a discrepancy note providing a reason why the answer is unknown.

Not Evaluated: This answer option should only be selected by the TSS if it is known that the information being requested cannot be obtained. This could be because the test in question was never performed on the patient or the TSS knows that the information requested was never disclosed.

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

Completed By (Interviewer Name in OpenClinica): _____ Completed Date: _____

#	Data Element	Entry Alternatives	Working Instructions
General Information			
BLGSP Project ID:			
*1	Is this a prospective tissue collection?	<input type="checkbox"/> Yes <input type="checkbox"/> No	Indicate whether the TSS providing tissue is contracted for prospective tissue collection. If the submitted tissue was collected after the date the BLGSP contract was executed, the tissue has been collected prospectively. 3088492
*2	Is this a retrospective tissue collection?	<input type="checkbox"/> Yes <input type="checkbox"/> No	Indicate whether the TSS providing tissue is contracted for retrospective tissue collection. If the submitted tissue was collected prior to the date the BLGSP contract was executed, the tissue has been collected retrospectively. 3088528
Patient Information			
Demographic Information			
*3	Date of Birth	_____/_____/_____ (month) (day) (year)	Provide the date the patient was born. 2896950 (month), 2896952 (day), 2896954 (year) <i>Note: The day of Birth is not required.</i>
*4	Gender	<input type="checkbox"/> Female <input type="checkbox"/> Male	Provide the patient's gender using the provided categories. 2200604
*5	Race (check all that apply)	<input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian/East Indian <input type="checkbox"/> White <input type="checkbox"/> Black/African American <input type="checkbox"/> Native Hawaiian or other Pacific Islander <input type="checkbox"/> Unknown	Provide the patient's race using the defined categories. 2192199 American Indian or Alaska Native: A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment. Asian: A person having origins in any of the original peoples of the far East, Southeast Asia, or in the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam. White: A person having origins in any of the original peoples of the four Europe, the Middle East, or North Africa. Black or African American: A person having origins in any of any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American." Native Hawaiian or other Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. Unknown: Could not be determined or unsure
6	Ethnicity	<input type="checkbox"/> Not Hispanic or Latino <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Not Reported <input type="checkbox"/> Unknown	Provide the patient's ethnicity using the defined categories. 2192217 Not Hispanic or Latino: A person not meeting the definition of Hispanic or Latino. Hispanic or Latino: A person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race. Not Reported: Not provided or available Unknown: Could not be determined or unsure
7	Height (at time of diagnosis)	_____ (cm)	Provide the patient's height (centimeters) at the time the patient was diagnosed with the tumor submitted for BLGSP. 649
8	Weight (at time of diagnosis)	_____ (kg)	Provide the patient's weight (kilograms) at the time the patient was diagnosed with the tumor submitted for BLGSP. 651
Survival Information			
*9	Vital Status (at date of last contact)	<input type="checkbox"/> Living <input type="checkbox"/> Deceased	The survival state of the person registered on the protocol. 5

Enrollment Form

Burkitt Lymphoma Genome Sequencing Project (BLGSP)

#	Data Element	Entry Alternatives	Working Instructions
*11	Date of Last Known Alive	____/____/____ (month) (day) (year)	Indicate the last date the patient was known to be alive, regardless of whether the patient, medical provider, family member or caregiver was contacted. 2975722 (month), 2975724 (day), 2975726 (year) <i>Note: The day of Last Known Alive is not required.</i>
†10	Date of Last Contact	____/____/____ (month) (day) (year)	If the patient is living, provide the date of last contact with the patient (as reported by the patient, medical provider, family member, or caregiver). 2897020 (month), 2897022 (day), 2897024 (year) <i>Note: The day of Last Contact is not required.</i> <i>Do not answer if patient is deceased.</i>
†12	Date of Death	____/____/____ (month) (day) (year)	If the patient is deceased, provide the month of death. 2897026 , (month) 2897028 (day), 2897030 (year) <i>Note: The day of Death is not required.</i>
13	Cause of Death <i>Only complete if patient is deceased.</i>	<input type="checkbox"/> Cancer Related <input type="checkbox"/> Non-Cancer Related <input type="checkbox"/> Unknown <input type="checkbox"/> Other (please specify)	Indicate the patient's cause of death. 2554674
14	Other Cause of Death <i>Only complete if "other" is selected above.</i>	_____	If the patient's cause of death was not included in the provided list, specify the patient's cause of death. 2004150
Patient Status (Regarding Submitted Tumor)			
*15	Did the patient receive neo-adjuvant therapy for the tumor submitted for BLGSP?	<input type="checkbox"/> Yes (<i>exclusion criterion</i>) <input type="checkbox"/> No	Indicate whether the patient received treatment (radiation, pharmaceutical, or both) prior to the procurement of the sample submitted for BLGSP. 3382737 <i>If the answer to this question is "yes", the submitted case is excluded.</i>
*16	Tumor Status (at time of last contact or death)	<input type="checkbox"/> Tumor free <input type="checkbox"/> With tumor <input type="checkbox"/> Unknown	Indicate whether the patient was tumor/disease free (i.e. free of the malignancy that yielded the sample submitted for the BLGSP study) at the date of last contact or death. 2759550
17	Performance Status: Eastern Cooperative Oncology Group (at diagnosis)	<input type="checkbox"/> 0: Fully active, able to carry on all pre-disease performance without restriction. <input type="checkbox"/> 1: Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work. <input type="checkbox"/> 2: Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours. <input type="checkbox"/> 3: Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours. <input type="checkbox"/> 4: Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair. <input type="checkbox"/> Unknown <input type="checkbox"/> Not Evaluated	Provide the Eastern Cooperative Oncology Group (ECOG) performance status of the patient at the time selected in the "timing" question below. 88
18	Performance Status: Karnofsky Score (at diagnosis)	<input type="checkbox"/> 100: Normal, no complaints, no evidence of disease <input type="checkbox"/> 90: Able to carry on normal activity; minor signs or symptoms of disease <input type="checkbox"/> 80: Normal activity with effort; some signs or symptoms of disease <input type="checkbox"/> 70: Cares for self, unable to carry on normal activity or to do active work <input type="checkbox"/> 60: Requires occasional assistance, but is able to care for most of his/her needs. <input type="checkbox"/> 50: Requires considerable assistance and frequent medical care <input type="checkbox"/> 40: Disabled, requires special care and assistance <input type="checkbox"/> 30: Severely disabled, hospitalization indicated. Death not imminent. <input type="checkbox"/> 20: Very sick, hospitalization indicated. Death not imminent. <input type="checkbox"/> 10: Moribund, fatal processes progressing rapidly <input type="checkbox"/> 0: Dead <input type="checkbox"/> Unknown <input type="checkbox"/> Not Evaluated	Provide the Karnofsky score for the patient at the time selected in the "timing" question below. 2003853
19	Tumor Response	<input type="checkbox"/> Progressive Disease <input type="checkbox"/> Stable Disease <input type="checkbox"/> Partial Response <input type="checkbox"/> Complete Response	Indicate the patient's measure of success after their primary treatment for the tumor submitted. Treatment includes surgery and adjuvant therapies. 2786727

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20	Adjuvant (Post-Operative) Radiation Therapy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient had adjuvant/ post-operative radiation therapy <i>for the tumor submitted</i> . 2005312																									
21	Adjuvant (Post-Operative) Pharmaceutical Therapy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient had adjuvant/ post-operative pharmaceutical therapy <i>for the tumor submitted</i> . 3397567																									
Patient History of Disease																												
HIV Status																												
*22	Is this patient HIV positive?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient is HIV positive. 2180464																									
†23	Date of HIV Diagnosis (if known) <i>Only complete if "Yes" is selected above.</i>	____ / ____ / ____ (month) (day) (year)	Provide the month the patient was diagnosed with HIV. 3579640 (month), 3579644 (day), 3579643 (year) <i>Note: The day of HIV Diagnosis is not required.</i>																									
24	Nadir CD4 Counts (at time of last contact)	_____ (cells/mm ³)	Provide the patient's Nadir CD4 counts, which are the lowest CD4 counts the patient has had. 2684395																									
25	CD4 Counts at Diagnosis of the Submitted Malignancy	_____ (cells/mm ³)	Provide the patient's CD4 Counts at the time the patient was diagnosed with the malignancy submitted for the BLGSP study. 2922654																									
26	HIV RNA load at Diagnosis of Submitted Malignancy	_____ (counts/mL)	Provide the HIV RNA load (also known as the "viral load") at the time the patient was diagnosed with the malignancy submitted for the BLGSP study. 2922674																									
27	Prior AIDS Defining Conditions	<input type="checkbox"/> Candidiasis of bronchi, trachea or lungs <input type="checkbox"/> Candidiasis, esophageal <input type="checkbox"/> CMV other than liver, spleen or nodes, onset at age >1month <input type="checkbox"/> CMV retinitis <input type="checkbox"/> Coccidioidomycosis, disseminated or extrapulmonary <input type="checkbox"/> Cryptococcosis, extrapulmonary <input type="checkbox"/> Cryptosporidiosis, chronic intestinal <input type="checkbox"/> Encephalopathy, HIV-related <input type="checkbox"/> Herpes simplex: chronic ulcers (> 1 month's duration) or bronchitis, pneumonitis or esophagitis (onset at age > 1 month) <input type="checkbox"/> Histoplasmosis, disseminated or extrapulmonary <input type="checkbox"/> Isosporiasis, chronic intestinal (> 1 mon) <input type="checkbox"/> Mycobacterium avium complex or Mycobacterium kansasii disseminated or extrapulmonary <input type="checkbox"/> Mycobacterium tuberculosis of any site, pulmonary, disseminated or extrapulmonary <input type="checkbox"/> Mycobacterium; other species or unidentified species, disseminated or extrapulmonary <input type="checkbox"/> Nocardiosis <input type="checkbox"/> Pneumocystis jirovecii pneumonia <input type="checkbox"/> Pneumonia, recurrent <input type="checkbox"/> Progressive multifocal leukoencephalopathy <input type="checkbox"/> Salmonella septicemia, recurrent <input type="checkbox"/> Toxoplasmosis of the brain, onset at age >1month <input type="checkbox"/> Wasting syndrome, due to HIV	Prior to the malignancy submitted for the BLGSP study, provide any AIDS defining conditions. 2679581																									
28	Co-Infections	<table border="1"> <thead> <tr> <th>Test</th> <th>(+)</th> <th>(-)</th> <th>Inconclusive</th> <th>Not Tested</th> </tr> </thead> <tbody> <tr> <td>HBV</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>HCV</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>HPV</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>KSHV/HHV8</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </tbody> </table>	Test	(+)	(-)	Inconclusive	Not Tested	HBV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	HCV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	HPV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	KSHV/HHV8	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Using the list provided, indicate whether the patient had any co-infections by providing the results of each of the tests listed.
		Test	(+)	(-)	Inconclusive	Not Tested																						
		HBV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
		HCV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
HPV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																								
KSHV/HHV8	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																								
	2180456																											
	2695021																											
	2230033																											
	3335773																											
29	HAART Treatment Prior to Diagnosis of Submitted Malignancy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient received Highly Active Antiretroviral Therapy (HAART) treatment prior to the diagnosis of the malignancy submitted for the BLGSP study. 3335156																									

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#	Data Element	Entry Alternatives	Working Instructions
30	HAART Treatment at Time of Diagnosis of Submitted Malignancy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient received Highly Active Antiretroviral Therapy (HAART) treatment at the time of the diagnosis of the malignancy submitted for the BLGSP study. 2922679
31	CDC HIV Risk Group	<input type="checkbox"/> Homosexual or bisexual contact <input type="checkbox"/> Heterosexual contact <input type="checkbox"/> IV drug user <input type="checkbox"/> Transfusion recipient <input type="checkbox"/> Hemophiliac <input type="checkbox"/> None <input type="checkbox"/> Unknown	Indicate whether the patient has a history of any of the listed HIV Risk Groups as defined by the Center for Disease Control (CDC). 2542215
Prior Malignancies			
*32	History of other malignancy	<input type="checkbox"/> Yes (<i>exclusion criterion</i>) <input type="checkbox"/> No	Indicate whether the patient has a history of malignancies, including synchronous or bilateral malignancies. 3382736 <i>If the answer to this question is "yes", the submitted case is excluded. This exclusion does not apply if the patient only has a history of non-melanoma skin cancer OR cervical in situ carcinoma.</i>
Prior Immunological Disease			
33	Patient History of Prior Immunological Disease	<input type="checkbox"/> Rheumatoid Arthritis <input type="checkbox"/> Sjogren's Syndrome <input type="checkbox"/> Systemic Lupus Erythematosus <input type="checkbox"/> Crohn's Disease <input type="checkbox"/> Ulcerative Colitis <input type="checkbox"/> Hashimoto's Thyroiditis <input type="checkbox"/> None <input type="checkbox"/> Other <input type="checkbox"/> Unknown	Indicate whether the patient has a history of any of the listed immunological diseases. 3233628
34	Patient History of Other Immunological Disease <i>Only complete if "other" is selected above.</i>	_____	Indicate whether the patient has a history of any of the listed immunological diseases. 3233629
35	Patient History of Prior Immunosuppressive Therapy for Immunological Disease	<input type="checkbox"/> Methotrexate <input type="checkbox"/> Cyclophosphamide <input type="checkbox"/> Azathioprine <input type="checkbox"/> Anti-TNF therapy <input type="checkbox"/> None <input type="checkbox"/> Other <input type="checkbox"/> Unknown	If the patient received immunosuppressive therapy for the immunological disease selected in the previous question, provide the type of immunosuppressive therapy given. 3233638
36	Other History of Prior Immunosuppressive Therapy <i>Only complete if "other" is selected above.</i>	_____	What was the other immunosuppressive therapy administered? 2873928
Prior Infectious Disease			
37	Patient History of Relevant Prior Infectious Disease	<input type="checkbox"/> Hepatitis B <input type="checkbox"/> Hepatitis C <input type="checkbox"/> H. Pylori <input type="checkbox"/> Malaria <input type="checkbox"/> None <input type="checkbox"/> Other <input type="checkbox"/> Unknown	Indicate whether the patient has a history of any of the listed infectious disease. 3233642
38	Patient History of Other Relevant Infectious Disease <i>Only complete if "other" is selected above.</i>	_____	If the patient has a history of relevant prior disease that was not included in the list, provide the infectious disease. 3233643
Pathologic Information			
*39	Histological Subtype	<input type="checkbox"/> Burkitt Lymphoma (BL), classic morphology <input type="checkbox"/> Burkitt Lymphoma (BL), atypical morphology <input type="checkbox"/> B-cell lymphoma, unclassifiable, with features intermediate between diffuse large B-cell lymphoma and Burkitt lymphoma <input type="checkbox"/> Diffuse large B-cell lymphoma (DLBCL), specify subtype [e.g. NOS, plasmablastic] <input type="checkbox"/> Unclassifiable B-cell lymphoma <input type="checkbox"/> Other, specify <input type="checkbox"/> Unknown	Using the patient's final diagnostic pathology report, provide the most detailed histological subtype available. 3081934
†40	Other Neoplasm Histologic Type, Specify <i>Only complete if "other" is</i>	_____	Free text field to specify the structural pattern of cancer cells used to define a microscopic diagnosis that is not already specified or mentioned.

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#	Data Element	Entry Alternatives	Working Instructions
	<i>selected above.</i>		3294805
*41	Site(s) of Nodal Involvement at Diagnosis <i>(Please check all that apply)</i>	<input type="checkbox"/> Axillary <input type="checkbox"/> Cervical <input type="checkbox"/> Epirochlear <input type="checkbox"/> Femoral <input type="checkbox"/> Hilar <input type="checkbox"/> Iliac <input type="checkbox"/> Iliac-common <input type="checkbox"/> Iliac-external <input type="checkbox"/> Inguinal <input type="checkbox"/> Mediastinal <input type="checkbox"/> Mesenteric <input type="checkbox"/> Occipital <input type="checkbox"/> Paraortic <input type="checkbox"/> Parotid <input type="checkbox"/> Popliteal <input type="checkbox"/> Retroperitoneal <input type="checkbox"/> Splenic <input type="checkbox"/> Supraclavicular <input type="checkbox"/> Submandibular <input type="checkbox"/> No known nodal involvement	Using the patient's medical record check all applicable boxes to identify the lymph node chain(s) that were involved by Burkitt lymphoma at the time of initial diagnosis. 2180591 <i>To select multiple sites of involvement, press the control button and select the sites of involvement. Your selections should be highlighted after you've selected.</i>
42	Extranodal Involvement At Diagnosis?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	2952463
43	Number of Extranodal Sites of Involvement Above <i>(to calculate the IPI)</i>	_____	Provide the total number of extranodal sites with lymphoma involvement. Use the previous three questions to determine this number. This information, along with other data provided, will be used by the Analysis Working Group (AWG) to calculate the International Prognostic Index (IPI). 3233242
†44	Site(s) of Extranodal Involvement At Diagnosis <i>(For Primary Clinical Involvement at Time of Diagnosis - Please check all that apply)</i> <i>Only complete if "yes" is selected above.</i>	<input type="checkbox"/> Adrenal Gland <input type="checkbox"/> Bone <input type="checkbox"/> Bone Marrow <input type="checkbox"/> Breast <input type="checkbox"/> Neck <input type="checkbox"/> Peripheral Blood <input type="checkbox"/> Skin <input type="checkbox"/> Soft Tissue (<i>muscle, ligaments, subcutaneous</i>) ENT & Eye <input type="checkbox"/> Eye <input type="checkbox"/> Larynx <input type="checkbox"/> Mandible <input type="checkbox"/> Maxilla <input type="checkbox"/> Nasal Soft Tissue <input type="checkbox"/> Nasopharynx <input type="checkbox"/> Ocular orbits <input type="checkbox"/> Oropharynx <input type="checkbox"/> Parotid Gland <input type="checkbox"/> Peri-orbital Soft Tissue <input type="checkbox"/> Salivary Gland <input type="checkbox"/> Sinus(es) <input type="checkbox"/> Thyroid gland Central Nervous System <input type="checkbox"/> Brain <input type="checkbox"/> Cerebrospinal Fluid <input type="checkbox"/> Epidural space <input type="checkbox"/> Leptomeninges Gastrointestinal/ Abdominal <input type="checkbox"/> Ascites <input type="checkbox"/> Appendix <input type="checkbox"/> Colon <input type="checkbox"/> Esophagus <input type="checkbox"/> Gallbladder <input type="checkbox"/> Liver <input type="checkbox"/> Pancreas <input type="checkbox"/> Rectum <input type="checkbox"/> Small Intestine <input type="checkbox"/> Stomach Genito-urinary Tract <input type="checkbox"/> Bladder <input type="checkbox"/> Epididymis <input type="checkbox"/> Kidney <input type="checkbox"/> Ovary <input type="checkbox"/> Prostate <input type="checkbox"/> Testicle <input type="checkbox"/> Uterus Mediastinal/ Intra-thoracic <input type="checkbox"/> Heart <input type="checkbox"/> Lung <input type="checkbox"/> Mediastinal Soft Tissue <input type="checkbox"/> Pericardium <input type="checkbox"/> Pleura <input type="checkbox"/> Not applicable <input type="checkbox"/> Other, please specify	Using the patient's medical record check all applicable boxes to identify the anatomic location of all site(s) of extranodal involvement by Burkitt lymphoma at the time of initial diagnosis. 3288482 <i>To select multiple sites of involvement, press the control button and select the sites of involvement. Your selections should be highlighted after you've selected.</i>
†45	Other Specified Site of Extranodal Involvement at Diagnosis <i>(For Primary Clinical Involvement)</i> <i>Only complete if "other" is selected above.</i>	_____	If all extranodal sites of involvement are not included in the list provided, please indicate any sites of extranodal involvement. 3234303
46	Maximum Tumor Bulk (<i>Dimension</i>)	_____ (cm)	After review of the entire medical record, record the length of the largest dimension/ diameter of a tumor, regardless of anatomical plane. 64215

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#	Data Element	Entry Alternatives	Working Instructions
*47	Anatomic Site of Maximum Tumor Bulk	<input type="checkbox"/> Adrenal <input type="checkbox"/> Bone <input type="checkbox"/> Bone Marrow <input type="checkbox"/> Breast <input type="checkbox"/> Neck <input type="checkbox"/> Peripheral Blood <input type="checkbox"/> Skin <input type="checkbox"/> Soft Tissue (<i>muscle, ligaments, subcutaneous</i>) Genito-urinary Tract <input type="checkbox"/> Bladder <input type="checkbox"/> Epididymis <input type="checkbox"/> Kidney <input type="checkbox"/> Ovary <input type="checkbox"/> Prostate <input type="checkbox"/> Testes <input type="checkbox"/> Uterus ENT & Eye <input type="checkbox"/> Eye <input type="checkbox"/> Larynx <input type="checkbox"/> Mandible <input type="checkbox"/> Maxilla <input type="checkbox"/> Nasal Soft Tissue <input type="checkbox"/> Nasopharynx <input type="checkbox"/> Ocular Orbits <input type="checkbox"/> Oropharynx <input type="checkbox"/> Parotid Gland <input type="checkbox"/> Peri-orbital Soft Tissue <input type="checkbox"/> Salivary Gland <input type="checkbox"/> Sinus <input type="checkbox"/> Thyroid Mediastinal/ Intra-thoracic <input type="checkbox"/> Heart <input type="checkbox"/> Lung <input type="checkbox"/> Mediastinal Soft Tissue <input type="checkbox"/> Pericardium <input type="checkbox"/> Pleura <input type="checkbox"/> Not applicable <input type="checkbox"/> Other <input type="checkbox"/> No Known Extranodal Involvement Gastrointestinal/ Abdominal <input type="checkbox"/> Ascites <input type="checkbox"/> Appendix <input type="checkbox"/> Colon <input type="checkbox"/> Esophagus <input type="checkbox"/> Gallbladder <input type="checkbox"/> Liver <input type="checkbox"/> Pancreas <input type="checkbox"/> Rectum <input type="checkbox"/> Small Intestine <input type="checkbox"/> Stomach Central Nervous System <input type="checkbox"/> Brain <input type="checkbox"/> Cerebrospinal Fluid <input type="checkbox"/> Epidural Space <input type="checkbox"/> Lepomeninges Lymph Nodes <input type="checkbox"/> Axillary <input type="checkbox"/> Cervical <input type="checkbox"/> Epitrochlear <input type="checkbox"/> Femoral <input type="checkbox"/> Hilar <input type="checkbox"/> Iliac <input type="checkbox"/> Iliac-common <input type="checkbox"/> Iliac-external <input type="checkbox"/> Inguinal <input type="checkbox"/> Mediastinal <input type="checkbox"/> Mesenteric <input type="checkbox"/> Occipital <input type="checkbox"/> Paraaortic <input type="checkbox"/> Parotid <input type="checkbox"/> Popliteal <input type="checkbox"/> Retroperitoneal <input type="checkbox"/> Splenic <input type="checkbox"/> Supraclavicular <input type="checkbox"/> Submandibular <input type="checkbox"/> No Known Nodal Involvement	Using the list of sites in the nodal and extranodal questions above, provide the anatomic site of the maximum tumor bulk. 3639616
Pathologic Diagnosis and Surgical Resection			
*48	Date of Initial Pathologic Diagnosis	____/____/____ (month) (day) (year)	Provide the date the patient was initially diagnosed with the malignancy submitted for BLGSP. This may or may not be the date of the surgical resection that yielded the tumor sample submitted for BLGSP. 2896956 (month), 2896958 (day), 2896960 (year) <i>Note: The day of Initial Pathologic Diagnosis is not required.</i>
49	Initial Pathologic Diagnosis Acquisition Method	<input type="checkbox"/> Incisional Biopsy <input type="checkbox"/> Excisional Biopsy <input type="checkbox"/> Core Biopsy <input type="checkbox"/> Blood Draw <input type="checkbox"/> Bone Marrow Aspirate <input type="checkbox"/> Other (please specify) <input type="checkbox"/> Unknown	Provide the method of the initial pathologic diagnosis. This is the method used on the date provided above. 2757941
50	Other Method of Initial Pathologic Diagnosis <i>Only complete if "other" is selected above.</i>	_____	If the method of initial pathologic diagnosis is not included in the list above, provide the method used. 2757948
51	Date of Tumor Sample Procurement	____/____/____ (month) (day) (year)	Provide the date of the surgical resection that yielded the tumor sample submitted for BLGSP. 3008197 (month), 3008195 (day), 3008199 (year)
Lymph Node Status			
52	Were Lymph Nodes Examined at the Time of Primary Resection?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether any lymph nodes were examined at the time of the primary resection. 2200396

Enrollment Form

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53	Number of Lymph Nodes Examined <i>Only complete if "yes" is selected above.</i>	_____	Provide the number of lymph nodes examined, if one or more lymph nodes were removed. 3			
54	Number of Lymph Nodes Positive by H&E light microscopy <i>Only complete if "yes" is selected above.</i>	_____	Provide the number of lymph nodes positive through hematoxylin and eosin (H&E) staining and light microscopy. 3086388			
55	Number of Lymph Nodes Positive by IHC Keratin Staining only <i>Only complete if "yes" is selected above.</i>	_____	Provide the number of lymph nodes positive through keratin immunohistochemistry (IHC) staining. 3086383			
56	Pathologic Positive Lymph Node Location(s) <i>(Check all that apply)</i> <i>Only complete if "yes" is selected above.</i>	<input type="checkbox"/> Pelvic (external iliac, internal iliac, obturator) <input type="checkbox"/> Common iliac <input type="checkbox"/> Paraaortic <input type="checkbox"/> Supraclavicular <input type="checkbox"/> Unknown <input type="checkbox"/> Other, specify	Using the patient's pathology/laboratory report, provide the location(s) of any positive lymph nodes. 3151519			
57	Other Positive Lymph Node <i>Only complete if "other" is selected above.</i>	_____	If the location of positive lymph nodes was not included in the list provide, please provide the location of positive lymph nodes. 3151522			
Staging and Histology of Bone Marrow						
*58	Tumor Stage (Follow Ann Arbor Criteria)	<input type="checkbox"/> Stage I <input type="checkbox"/> Stage II <input type="checkbox"/> Stage III <input type="checkbox"/> Stage IV	Using the patient's pathology/laboratory report in conjunction with the patient's medical record, select the clinical or pathological stage as defined by the American Joint Committee on Cancer (AJCC). 3203222			
*59	Are "B" Symptoms Present?	<input type="checkbox"/> Yes <input type="checkbox"/> No	Using the patient's medical record, indicate whether there is documentation of "B" symptoms. <i>Note: "B" symptoms are defined as unexplained fevers, drenching night sweats, or unexplained weight loss of more than 10% of usual body weight in the six months prior to lymphoma diagnosis.</i> 2902402			
*60	Lymphomatous Involvement of Extranodal "E" Site?	<input type="checkbox"/> Yes <input type="checkbox"/> No	Using the patient's medical record, indicate whether there is documentation of extranodal site involvement. <i>Note: If the answer is "Yes", the anatomic site(s) of extranodal involvement should be included inextranodal site question above.</i> 3364582			
61	Presence of Malignant Cells in Bone Marrow by Histology	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate if malignant cells are histologically confirmed in the patient's bone marrow. 2180550			
62	Histology of Bone Marrow Samples	<input type="checkbox"/> Concordant Histology <input type="checkbox"/> Discordant Histology <input type="checkbox"/> Unknown	If malignant cells are present in the bone marrow at the time of initial staging workup, determine if the histologic diagnosis of the bone marrow is concordant with the diagnosis of BL. 3233401			
Tests Performed						
LDH Level (at the time of staging)						
*63	LDH Level	_____ (IU)	Record the result of the LDH lab test performed during the staging workup. 2798766			
*64	LDH Level Upper Limit for Normal at Facility	_____ (IU)	Record the upper limit of the normal range of the LDH lab test performed at the reporting facility. 2953115			
Genetic Testing						
65	Tests Performed for Immunophenotyping	(+) (-) Indeterminate	Indicate all tests performed for immunophenotypic analysis in order to classify clonal subgroups. 3234614 (test performed) , 3234626 (Result)			
		Ki-67 > 90%		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		CD10 > 30%		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		BCL2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Enrollment Form

Burkitt Lymphoma Genome Sequencing Project (BLGSP)

#	Data Element	Entry Alternatives	Working Instructions
		CD20 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> BCL6 > 30% <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> CD3 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Other <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
66	Other Tests Performed for Immunophenotyping (please specify) <i>Only complete if "other" is selected in previous question.</i>	_____	Indicate all tests performed for immunophenotypic analysis in order to classify clonal subgroups. 2516429
67	B-cell Immunophenotype Methodology	<input type="checkbox"/> Immunohistochemistry <input type="checkbox"/> Flow Cytometry, not otherwise specified <input type="checkbox"/> Immunofluorescence <input type="checkbox"/> Other	If B-cell genotype was performed, indicate the testing method used. 64540

Genetic Abnormalities

68	Genetic Abnormalities	N T G A L O	Indicate all genetic abnormalities for which the patient was tested. 3234675 , 3234680 N = Normal T = Translocation G = Gain L = Loss A = Amplification O = Other
		C-MYC <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
		BCL2 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
69	Other Genetic Abnormalities (please specify)	N T G A L O	Specify any other genetic abnormalities not in the provided list for which the patient was tested. 3234685 , 3234680
		_____ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
		_____ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
		_____ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
70	Other Results of Testing for Genetic Abnormality	Other Results	Specify any other results of testing for genetic abnormalities not in the provided list. 4459354
		C-MYC	
		BCL2	
		BCL6	
71	Methodology Used in Testing for Genetic Abnormality <i>Only complete if patient had a genetic abnormality.</i>	1 2 3 4	If the patient was tested for a specific genetic abnormality, indicate the testing method used to perform each analysis. 3234684 Methodology Code: 1 = PCR 2 = Southern Blot 3 = FISH 4 = Cytogenetic
		C-MYC <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
		BCL2 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
		BCL6 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
72	Methodology Used to Determine EBV Status of Malignant Cells	<input type="checkbox"/> EBER in situ Hybridization <input type="checkbox"/> LMP Immunohistochemistry <input type="checkbox"/> EBV PCR <input type="checkbox"/> Unknown	If the patient's EBV status was positive, provide the testing method used to determine the EBV status of the malignant cells. 3233656
		<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Unknown	
		<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Unknown	
		<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Unknown	
74	If EBV status is positive, provide the percent positive. (does not include background positives) <i>Only complete if "positive" is selected above.</i>	_____ (%)	If the patient's EBV status was positive, provide the percentage of EBV positive malignant cells. Do not include the number of background positives. 3233649

New Tumor Event Information Complete this section if the patient had a new tumor event. If the patient did not have a new tumor event (or if the TSS does not know) indicate this in the question below, and the remainder of this section can be skipped.

Enrollment Form

Burkitt Lymphoma Genome Sequencing Project (BLGSP)

#	Data Element	Entry Alternatives	Working Instructions
i*	New Tumor Event After Initial Treatment?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient had a new tumor event (e.g. metastatic, recurrent, or new primary tumor) after initial treatment. 3121376 <i>If the patient did not have a new tumor event or if this is unknown, the remaining questions can be skipped.</i>
ii†	Date of New Tumor Event	_____ <i>Month Day Year</i>	If the patient had a new tumor event, provide the date of diagnosis for this new tumor event. 3104044 (Month), 3104042 (Day), 3104046 (Year)
iii	Type of New Tumor Event	<input type="checkbox"/> Locoregional Recurrence <input type="checkbox"/> Distant Metastasis <input type="checkbox"/> New Primary Tumor	Indicate whether the patient's new tumor event was a locoregional recurrence or a distant metastasis of the tissue submitted for TCGA; or a new primary tumor. 3119721
iv	Anatomic Site of New Tumor Event	<input type="checkbox"/> Bone <input type="checkbox"/> Lung <input type="checkbox"/> Liver <input type="checkbox"/> Retroperitoneum <input type="checkbox"/> Lymph Node(s) <input type="checkbox"/> Other, specify	Indicate the site of this new tumor event. 3108271
v	Other Site of New Tumor Event	_____	If the site of the new tumor event is not included in the provided list, describe the site of this new tumor event. 3128033
vi	Diagnostic Evidence of Recurrence / Relapse (check all that apply)	<input type="checkbox"/> Biopsy w/Histologic Confirmation <input type="checkbox"/> Convincing Imaging (i.e. CT, PET, MRI) <input type="checkbox"/> Positive Biomarker(s)	Indicate the procedure or testing method used to diagnose tumor recurrence or relapse. 2786205
vii	Additional Surgery for New Tumor Event	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Using the patient's medical records, indicate whether the patient had surgery for the new metastatic tumor event in question. 3427611
viii	Additional Treatment of New Tumor Event Radiation Therapy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient received radiation treatment for this new tumor event. 3427615
ix	Additional Treatment of New Tumor Event Pharmaceutical Therapy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the patient received pharmaceutical treatment for this new tumor event. 3427616
Patient Status			
*75	Is This Patient Lost to Follow-up?	<input type="checkbox"/> Yes <input type="checkbox"/> No	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. 61333 <i>If the patient is lost to follow-up or deceased at the time of enrollment, follow-up forms are not required.</i>

 Principal Investigator (*Printed Name*)

 Principal Investigator (*Signature*)

 Date

I acknowledge that the above information provided by my institution is true and correct and has been quality controlled.