

## Follow-up Form

### Burkitt Lymphoma Genome Sequencing Project (BLGSP)

**Instructions:** The Clinical Data needed to complete this Follow-up Form should be collected for each qualified case in the Burkitt Lymphoma Genome Sequencing Project (BLGSP) at 12 and 24 months after the date of patient consent. The Tissue Source Site (TSS) should complete this Follow-up Form within 60 days after the 12 and 24 month patient consent anniversary for all qualified cases indicated by the Office of Cancer Genomics (OCG). Questions regarding this form should be sent to Nationwide Children's Hospital 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. If for example, a test was not performed the results of that test cannot be provided because it was "Not Evaluated."

Tissue Source Site (TSS): \_\_\_\_\_ TSS Identifier: \_\_\_\_\_ TSS Unique Patient Identifier: \_\_\_\_\_

Completed By (Interviewer Name in OpenClinica): \_\_\_\_\_ Completed Date: \_\_\_\_\_

#	Data Element	Entry Alternatives	Working Instructions
<b>Patient Information</b>			
<b>Survival Information</b>			
*1	Vital Status (at date of last contact)	<input type="checkbox"/> Living <input type="checkbox"/> Deceased <input type="checkbox"/> Lost to follow-up	Indicate whether the patient was living or deceased at the date of last contact, or has been lost to follow-up as defined by the ACoS Commission on Cancer. This only includes cases where updated follow-up information has not been collected within the past 15 months and all efforts to contact the patient have been exhausted (this includes reviewing death records). <i>If the patient is lost to follow-up, the remaining questions can be left unanswered. If the patient is deceased and a BLGSP follow-up form has not yet been completed, the remaining applicable questions should be completed.</i> <a href="#">5</a>
†2	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). <a href="#">2897020</a> (month), <a href="#">2897022</a> (day), <a href="#">2897024</a> (year) <i>Do not answer if patient is deceased.</i> <i>Note: The day of Last Contact is not required.</i>
*3	Date 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. <a href="#">2975722</a> (month), <a href="#">2975724</a> (day), <a href="#">2975726</a> (year) <i>Note: The day of Last Known Alive is not required.</i>
†4	Date of Death	____/____/____ (month) (day) (year)	If the patient is deceased, provide the date of death. <a href="#">2897026</a> , (month) <a href="#">2897028</a> (day), <a href="#">2897030</a> (year) <i>Note: The day of Death is not required.</i>
<b>Patient Status (Regarding Submitted Tumor)</b>			
*5	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. <a href="#">2759550</a>
*6	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 for the tumor submitted. <a href="#">2005312</a>
*7	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 for the tumor submitted. <a href="#">3397567</a>
8	Measure of Success of Outcome at the Completion of this Follow-up Submission (at time of last contact)	<input type="checkbox"/> Progressive disease <input type="checkbox"/> Persistent disease <input type="checkbox"/> Stable disease <input type="checkbox"/> Partial Response <input type="checkbox"/> Complete Response <input type="checkbox"/> Unknown <input type="checkbox"/> Not Applicable (Treatment Ongoing)	Text term to describe the overall outcome of treatment up to the point of the current data submission. <a href="#">3104050</a>
<b>HIV Status</b>			
*9	HIV antibody status	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Unknown	Indicate whether the patient is HIV positive. <a href="#">2180464</a>

## Follow-up Form

### Burkitt Lymphoma Genome Sequencing Project (BLGSP)

#	Data Element	Entry Alternatives	Working Instructions
†10	Date of HIV Diagnosis (if known)	____ / ____ / ____ (month) (day) (year)	Provide the date the patient was diagnosed with HIV. <a href="#">3579640</a> (month), <a href="#">3579644</a> (day), <a href="#">3579643</a> (year) <i>Note: The day of HIV Diagnosis is not required.</i>
11	Nadir CD4 Counts (at time of last contact)	_____ (cells/mm <sup>3</sup> )	Provide the patient's most recent Nadir CD4 counts, which are the lowest CD4 counts the patient has had. <a href="#">2684395</a>
<b>New Tumor Event Information</b> 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. Please Note: The New Tumor Event section on OpenClinica can be completed multiple times, if the patient had multiple New Tumor Events.			
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. <a href="#">3121376</a> If the patient did not have a new tumor event or if this is unknown, the remaining questions can be skipped.
ii†	Date of New Tumor Event	____ / ____ / ____ Month Day Year	If the patient had a new tumor event, provide the date of diagnosis for this new tumor event. <a href="#">3104044</a> (Month), <a href="#">3104042</a> (Day), <a href="#">3104046</a> (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; or a new primary tumor. <a href="#">3119721</a>
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. <a href="#">3108271</a>
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. <a href="#">3128033</a>
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. <a href="#">2786205</a>
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. <a href="#">3427611</a>
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. <a href="#">3427615</a>
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. <a href="#">3427616</a>

---

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.*