

Follow-Up Form

Pheochromocytoma and Paraganglioma (PCPG)

Instructions: The Follow-up Form is to be completed 12 months after a case enters the Biospecimen Core Resource (BCR). 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. Please direct any questions to the Clinical Outreach team at the BCR.

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 TCGA 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 on OpenClinica): _____ Completed Date: _____

General Information

#	Data Element	Entry Alternatives	Working Instructions
1*	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 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 the Social Security death index). If the patient is lost to follow-up, the remaining questions can be left unanswered. 61333 <i>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.</i>

Follow-Up Information

2*	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. If the patient did have adjuvant radiation, the Radiation Supplemental Form should be completed. 2005312
3*	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. If the patient did have adjuvant pharmaceutical therapy, the Pharmaceutical Supplemental Form should be completed. 3397567
4	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 at the date of last contact or death. 2759550
5*	Vital Status (at date of last contact)	<input type="checkbox"/> Living <input type="checkbox"/> Deceased	Indicate whether the patient was living or deceased at the date of last contact. 5

Date of Last Contact (If patient is living)

6	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)
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Date of Death

7	Date of Death	_____ Month Day Year	If the patient is deceased, provide the date of death. 2897026 (Month), 2897028 (Day), 2897030 (Year)
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#	Data Element	Entry Alternatives	Working Instructions
8	Performance Status Scale: Karnofsky Score <i>(To be taken prior to surgery/treatment)</i>	<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 is 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"/> Not Evaluated <input type="checkbox"/> Unknown	Using the patient’s medical records, provide the Karnofsky performance status score at the time provided in the “Timing” question below. 2003853
9	Performance Status Scale: Eastern Cooperative Oncology Group (ECOG) <i>(To be taken prior to surgery/treatment)</i>	<input type="checkbox"/> 0 – Asymptomatic <input type="checkbox"/> 1 – Symptomatic but fully ambulatory <input type="checkbox"/> 2 – Symptomatic but in bed less than 50% of the day <input type="checkbox"/> 3 – Symptomatic and in bed more than 50% of the day <input type="checkbox"/> 4 – Bedridden <input type="checkbox"/> Not Evaluated <input type="checkbox"/> Unknown	Using the patient’s medical records, provide the ECOG performance status score at the time provided in the “Timing” question below. 88
10	Performance Status Scale: Timing	<input type="checkbox"/> Pre-Operative <input type="checkbox"/> Pre-Adjuvant <input type="checkbox"/> Post-Adjuvant <input type="checkbox"/> Other <input type="checkbox"/> Unknown	Indicate the patient’s status during the last documented ECOG and/or Karnofsky performance status score. 2792763

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.

Note: The New Tumor Event section on OpenClinica can be completed multiple times, if the patient had multiple New Tumor Events.

#	Data Element	Entry Alternatives	Working Instructions
11*	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 If the patient did not have a new tumor event or if this is unknown, the remaining questions can be skipped.
12	Type of New Tumor Event	<input type="checkbox"/> Locoregional Recurrence <input type="checkbox"/> Distant Metastasis <input type="checkbox"/> Biochemical Evidence of Disease <input type="checkbox"/> New Primary Tumor	Indicate whether the patient’s new tumor event was a locoregional recurrence, a distant metastasis or a new primary tumor. A new primary tumor is a tumor with a different histology as the tumor submitted to TCGA. 3119721
13	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
14	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
15	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)

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#	Data Element	Entry Alternatives	Working Instructions
16	How was this New Tumor Event confirmed?	<input type="checkbox"/> Imaging <input type="checkbox"/> Pathology <input type="checkbox"/> Unknown	If the patient had a new tumor event, provide the method used to confirm the diagnosis. 3186701

Principal Investigator or Designee Signature

Print Name

____/____/_____
Date