**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

<table>
<thead>
<tr>
<th>#</th>
<th>Data Element</th>
<th>Entry Alternatives</th>
<th>Working Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1*</td>
<td>Is this Patient Lost to Follow-up?</td>
<td>☐ Yes ☐ No</td>
<td>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. <strong>61333</strong></td>
</tr>
<tr>
<td>2*</td>
<td>Adjuvant (Post-Operative) Radiation Therapy</td>
<td>☐ Yes ☐ No ☐ Unknown</td>
<td>Indicate whether the patient had adjuvant/post-operative radiation therapy. <strong>IF the patient did have adjuvant radiation, the Radiation Supplemental Form should be completed. 2005312</strong></td>
</tr>
<tr>
<td>3*</td>
<td>Adjuvant (Post-Operative) Pharmaceutical Therapy</td>
<td>☐ Yes ☐ No ☐ Unknown</td>
<td>Indicate whether the patient had adjuvant/post-operative pharmaceutical therapy. <strong>IF the patient did have adjuvant pharmaceutical therapy, the Pharmaceutical Supplemental Form should be completed. 3397567</strong></td>
</tr>
<tr>
<td>4</td>
<td>Tumor Status (at time of last contact or death)</td>
<td>☐ Tumor free ☐ With tumor ☐ Unknown</td>
<td>Indicate whether the patient was tumor/disease free at the date of last contact or death. <strong>2759550</strong></td>
</tr>
<tr>
<td>5*</td>
<td>Vital Status (at date of last contact)</td>
<td>☐ Living ☐ Deceased</td>
<td>Indicate whether the patient was living or deceased at the date of last contact. <strong>5</strong></td>
</tr>
</tbody>
</table>

### Follow-Up Information

**Date of Last Contact (If patient is living)**

<table>
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<tr>
<td>6</td>
<td>Date of Last Contact</td>
<td>Month Day Year</td>
<td>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). <strong>2897020</strong> (Month), <strong>2897022</strong> (Day), <strong>2897024</strong> (Year)</td>
</tr>
</tbody>
</table>

**Date of Death**

<table>
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<tr>
<td>7</td>
<td>Date of Death</td>
<td>Month Day Year</td>
<td>If the patient is deceased, provide the date of death. <strong>2897026</strong> (Month), <strong>2897028</strong> (Day), <strong>2897030</strong> (Year)</td>
</tr>
<tr>
<td>#</td>
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</table>
| 8  | Performance Status Scale: Karnofsky Score (To be taken prior to surgery/treatment) | □ 100 – Normal, no complaints, no evidence of disease  
□  90 – Able to carry on normal activity; minor signs or symptoms of disease  
□  80 – Normal activity with effort; some signs or symptoms of disease  
□  70 – Cares for self, unable to carry on normal activity or to do active work  
□  60 – Requires occasional assistance, but is able to care for most of his/her needs  
□  50 – Requires considerable assistance and frequent medical care  
□  40 – Disabled, requires special care and assistance  
□  30 – Severely disabled, hospitalization indicated. Death is not imminent.  
□  20 – Very sick, hospitalization indicated. Death not imminent  
□  10 – Moribund, fatal processes progressing rapidly  
□  0 – Dead  
□  Not Evaluated  
□  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) (To be taken prior to surgery/treatment) | □ 0 – Asymptomatic  
□ 1 – Symptomatic but fully ambulatory  
□ 2 – Symptomatic but in bed less than 50% of the day  
□ 3 – Symptomatic and in bed more than 50% of the day  
□ 4 – Bedridden  
□  Not Evaluated  
□  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      | □ Pre-Operative  
□ Pre-Adjuvant  
□ Post-Adjuvant  
□ Other  
□ 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.*

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| 11 | New Tumor Event After Initial Treatment? | □ Yes  
□ No  
□ Unknown | Indicate whether the patient had a new tumor event (e.g. metastatic, recurrent, or new primary tumor) after initial treatment.  
3121376 |
| 12 | Type of New Tumor Event              | □ Locoregional Recurrence  
□ Distant Metastasis  
□ Biochemical Evidence of Disease  
□ 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     | □ Bone  
□ Lung  
□ Lymph Node(s)  
□ Liver  
□ Retroperitoneum  
□ 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              | Month  Day  Year | 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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<td>16</td>
<td>How was this New Tumor Event confirmed?</td>
<td>□ Imaging</td>
<td>If the patient had a new tumor event, provide the method used to confirm the diagnosis.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Pathology</td>
<td>3186701</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unknown</td>
<td></td>
</tr>
</tbody>
</table>

Principal Investigator or Designee Signature ___________________________  Print Name ___________________________ Date __/__/___