

Follow-up Form Adrenocortical Carcinoma

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 in 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

#	Data Element	Entry Alternatives	Working Instructions
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 <i>for the tumor submitted for TCGA</i> . 2005312 <i>If the patient did have adjuvant radiation, the Radiation Supplemental Form should be completed.</i>
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 <i>for the tumor submitted for TCGA</i> . 3397567 <i>If the patient did have adjuvant pharmaceutical therapy, the Pharmaceutical Supplemental Form should be completed.</i>
4	Did the patient receive adjuvant mitotane therapy?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Not Applicable (patient had macroscopic disease and/or non-resectable disease)	Indicate whether the patient received mitotane treatment after the submitted tumor was removed. 3646377
5	Did the patient attain therapeutic mitotane levels > 14 mg/L?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	If the patient received adjuvant mitotane treatment, indicate whether the patient attained therapeutic mitotane levels. 3646378

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#	Data Element	Entry Alternatives	Working Instructions
6	Clinical Status Within Three (3) Months of Surgery	<input type="checkbox"/> No Imaging Evidence of Disease <input type="checkbox"/> Persistent Locoregional Disease <input type="checkbox"/> Persistent Distant Metastatic Disease <input type="checkbox"/> Biochemical Evidence of Disease	Indicate the patient's clinical status within three months of the surgery related to the tumor submitted for TCGA. 3186684
7	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
8	Measure of Success of Outcome at the Completion of Initial First Course Treatment (surgery and adjuvant therapies)	<input type="checkbox"/> Progressive Disease <input type="checkbox"/> Stable Disease <input type="checkbox"/> Partial Response <input type="checkbox"/> Complete Response <input type="checkbox"/> Not Applicable (treatment ongoing) <input type="checkbox"/> Unknown	Provide the patient's response to their initial first course treatment (surgery and/or adjuvant therapies). 2786727
9	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
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) Do not answer if patient is deceased.
11	Date of Death	____ ____ ____ Month Day Year	If the patient is deceased, provide the date of death. 2897026 (Month), 2897028 (Day), 2897030 (Year)

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.

#	Data Element	Entry Alternatives	Working Instructions
12	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.
13	Type of New Tumor Event	<input type="checkbox"/> Locoregional Recurrence <input type="checkbox"/> Distant Metastasis <input type="checkbox"/> Biochemical Evidence of Disease	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
14	Anatomic Site of New Tumor Event	<input type="checkbox"/> Bone <input type="checkbox"/> Lung <input type="checkbox"/> Liver <input type="checkbox"/> Soft Tissue <input type="checkbox"/> Peritoneum/ Tumor Bed <input type="checkbox"/> Retroperitoneum <input type="checkbox"/> Lymph Node(s) <input type="checkbox"/> Other, specify	Indicate the site of this new tumor event. 3108271
15	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
16	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)
17	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
18	Evidence of Histologic Progression	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Indicate whether the new tumor event had evidence of histologic progression (i.e. transition from low grade to high grade). 3181376
19	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 tumor event in question. 3427611

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#	Data Element	Entry Alternatives	Working Instructions
<u>20</u>	Date of Additional Surgery for New Tumor Event	____ _ <i>Month</i> <i>Day</i> <i>Year</i>	If the patient had surgery for the new tumor event, provide the date this surgery was performed. 3427612 (Month), 3427613 (Day), 3427614 (Year)
<u>21</u>	Additional treatment for New Tumor Event: <i>Radiation Therapy</i>	<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
<u>22</u>	Additional treatment for New Tumor Event: <i>Pharmaceutical Therapy</i>	<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

Principal Investigator or Designee Signature_____
Print Name____/____/_____
Date