Follow-Up Form
Kidney Papillary (KIRP)

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 cannot answer the question because the answer is not known at the TSS. 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 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 on OpenClinica)*: _____Completed Date: _____

General Information

#	Data Element	Entry Alternatives	Working Instructions
1*	Has this TSS received permission from the NCI to provide time intervals as a substitute for requested dates on this form?	☐ Yes ☐ No	If the answer to this question is yes, time intervals must be provided instead of dates, as indicated throughout this form. Provided time intervals must begin with the date of initial pathologic diagnosis (i.e. biopsy or resection). Only provide interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.
2	Reason For Follow-up Form Submission	☐ Scheduled (Routine) Follow-up Submission ☐ Additional New Tumor Event	Indicate the reason for submission of this follow-up form. If scheduled follow-up, complete entire form. If additional new tumor event, complete only questions pertaining *to new tumor*. 3233305
3	Is This Patient Lost to Follow-up?	☐ Yes ☐ 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 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.
Primary Treatment			
	Adjuvant (Post-Operative) Radiation Therapy	☐ Yes ☐ No ☐ 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
	Adjuvant (Post-Operative) Pharmaceutical Therapy	☐ Yes ☐ No ☐ 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
	Measure of Success of Outcome at the Completion of Initial First Course Treatment (surgery and adjuvant therapies)	☐ Progressive Disease ☐ Stable Disease ☐ Partial Response ☐ Complete Response ☐ Not Applicable ☐ Unknown	Provide the patient's response to their initial first course treatment. 2786727

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Patient Status			
	Vital Status *(at date of last contact)*	☐ Living ☐ Deceased	Indicate whether the patient was living or deceased at the date of last contact. 5
Date of Last Contact (If patient is living)			
28*	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)
29	Number of Days from Date of Initial Pathologic Diagnosis to Date of Last Contact	_____	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease described on this form to the date of last contact. 3008273 Only provide Interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.
Date of Death			
30*	Date of Death	___ ___ ___ ___ ___ ___ ___ ___ *Month* *Day* *Year*	If the patient is deceased, provide the date of death. 2897026 (Month), 2897028 (Day), 2897030 (Year)
31	Number of Days from Date of Initial Pathologic Diagnosis to Date of Death	_____	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease described on this form to the date of death. 3165475 Only provide Interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.
32	Tumor Status *(at time of last contact or death)*	☐ Tumor free ☐ With tumor ☐ Unknown Tumor Status	Indicate whether the patient was tumor/disease free at the date of last contact or death. 2759550
Performance Status			
	Performance Status Score: Karnofsky Score (Pre-Operative)	☐ 100 ☐ 90 ☐ 80 ☐ 70 ☐ 60 ☐ 50 ☐ 40 ☐ 30 ☐ 20 ☐ 10 ☐ 0 ☐ Unknown ☐ Not Evaluated	Provide the patient's Karnofsky Score using the defined categories. This score represents the functional capabilities of the patient. 2003853 ***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 ***30:*** Severely disabled ***20:*** Very sick; requiring hospitalization ***10:*** Moribund; fatal processes progressing rapidly ***0:*** Dead ***Not Evaluated:*** *Not provided or available.* ***Unknown:*** *Could not be determined or unsure.*
	Performance Status Score: Eastern Cooperative Oncology Group (ECOG)	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ Unknown ☐ Not Evaluated	Provide the patient's Eastern Cooperative Oncology Group (ECOG) score using the defined categories. This score represents the functional performance status of the patient. 88 ***0:*** Asymptomatic ***1:*** Symptomatic, but fully ambulatory ***2:*** Symptomatic, in bed less than 50% of day ***3:*** Symptomatic, in bed more than 50% of day, but not bed-ridden ***4:*** Bed-ridden ***Not Evaluated:*** *Not provided or available.* ***Unknown:*** *Could not be determined or unsure.*
	Performance Status Score: Timing	☐ Post Adjuvant Therapy ☐ At Recurrence/Progression of Disease ☐ Post Secondary Therapy ☐ Unknown ☐ Not Evaluated	Provide a time reference for the Karnofsky score and/or the ECOG score using the defined categories. 2792763

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#	Data Element	Entry Alternatives	Working Instructions
New Tumor Event Information *Please verify that new tumor event information has not previously been reported on the Enrollment Form or on a Prior Follow-up Form.*			
49*	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 for the tumor submitted to TCGA. If the patient had multiple new tumor events, a follow-up form should be completed for each new tumor event. 3121376 *If the patient did not have a new tumor event or if this is unknown, the remaining questions can be skipped.*
Date of New Tumor Event after Initial Treatment			
50	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)
51	Number of Days from Date of Initial Pathologic Diagnosis to Date of New Tumor Event After Initial Treatment	_____	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease to the date of new tumor event after initial treatment. 3392464 Only provide Interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.
52	Additional Surgery for New Tumor Event Loco-regional Procedure	☐ Yes ☐ No ☐ Unknown	Using the patient's medical records, indicate whether the patient had surgery for the new loco-regional tumor event in question. 3008755
Date of Additional Surgery for New Tumor Event Loco-Regional			
53	Date of Additional Surgery for New Tumor Event Locoregional	___ ___ ___ ___ ___ ___ ___ ___ *Month* *Day* *Year*	If the patient had surgery for the new loco-regional tumor event, provide the date of surgery for this new loco-regional tumor event. 2897032 (Month), 2897034 (Day), 2897036 (Year)
54	Number of Days from Date of Initial Pathologic Diagnosis to Date of Additional Surgery for New Tumor Event Locoregional	_____	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease to the date of additional surgery for new tumor event (Local-Regional). 3408572 Only provide Interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.
55	Additional Surgery for New Tumor Event Metastasis Procedure	☐ Yes ☐ No ☐ Unknown	Using the patient's medical records, indicate whether the patient had surgery for the new metastatic tumor event in question. 3008757
Date of Additional Surgery for New Tumor Event Metastatic			
56	Date of Additional Surgery for New Tumor Event Metastatic	___ ___ ___ ___ ___ ___ ___ ___ *Month* *Day* *Year*	If the patient had surgery for the new metastatic tumor event, provide the date of surgery for this new metastatic tumor event. 2897038 (Month), 2897040 (Day), 2897042 (Year)
57	Number of Days from Date of Initial Pathologic Diagnosis to Date of Additional Surgery for New Tumor Event Metastasis	_____	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease to the date of additional surgery for new tumor event (metastasis). 3408682 Only provide Interval data if you have received permission from the NCI to provide time intervals as a substitute for requested dates on this form.
Additional Treatment			
58	Additional treatment for New Tumor Event: *Radiation Therapy*	☐ Yes ☐ No ☐ Unknown	Indicate whether the patient received radiation treatment for this new tumor event. 3427615
59	Additional treatment for New Tumor Event: *Pharmaceutical Therapy*	☐ Yes ☐ No ☐ Unknown	Indicate whether the patient received pharmaceutical treatment for this new tumor event. 3427616

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	Measure of Success of Outcome at the Completion of this Follow-up Submission	☐ Progressive Disease ☐ Stable Disease ☐ Partial Response ☐ Complete Response ☐ Not Applicable ☐ Unknown	Provide the patient's outcome of treatment up to the point of the current follow-up data submission 3104050

_____ _____ ___ ___/ ___ ___/ ___ ___ ___ ___

Principal Investigator or Designee Signature | Print Name | Date (Month/Day/Year)