

## Supplementary Data:

### Appendix A: Survey Questions

1. We are interested in understanding possible challenges one may face when participating in a clinical trial of receiving medication before kidney removal for patients with kidney cancer and how we can make participation in these trials easier and better. We would greatly appreciate your participation. Your answers are confidential.
2. What was your month and year of initial kidney cancer diagnosis?  
Month: \_\_\_\_\_  
Year: \_\_\_\_\_
3. What was your clinical stage at diagnosis?
  - Localized (i.e. cancer only in the kidney)
  - Spread to lymph nodes (i.e. just outside of the kidney)
  - Spread to other parts of the body (i.e. lungs, liver, bones, etc)
  - Don't know
  - Other
4. How was your tumor described to you as the type of kidney cancer?
  - No biopsy or tumor removed in order to define pathologic tumor type
  - Clear cell renal cell carcinoma
  - Papillary renal cell carcinoma
  - Chromophobe renal cell carcinoma
  - Medullary renal cell carcinoma
  - Collecting duct renal cell carcinoma
  - Translocation renal cell carcinoma
  - Rhabdoid renal cell carcinoma
  - Sarcomatoid renal cell carcinoma
  - Other. If other, please specify \_\_\_\_\_
  - Don't know
5. Was your tumor removed by surgery?
  - Yes
  - No
  - Don't know
6. If yes, was your kidney totally removed or partially removed?
  - Kidney totally removed (i.e. nephrectomy)
  - Partially removed (i.e. partial nephrectomy)
  - Don't know
7. Have you ever had the tumor come back in a similar or different location (i.e. a tumor recurrence)?
  - Yes
  - No
  - Don't know
8. A clinical trial is research which studies new tests and treatment and evaluates their effects on human health outcomes. Have you *ever* participated in \_\_\_\_ (check all that apply)?

- A clinical trial, unrelated to kidney cancer
- A clinical trial that was done to study something about kidney cancer
- Specifically, a clinical trial where treatment was given prior to surgery
- Unsure what type, but I did participate
  
- I have never participated to my knowledge

9. If unsure, can you provide us with any additional information on the type of clinical trial \_\_\_\_\_

10. What was your age when you were diagnosed with kidney cancer?

- <30
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- >79

11. What is your gender?

- Female
- Male
- Non-binary/third gender
- Prefer not to say

12. What is your race?

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Mixed race
- Prefer not to answer
- Other \_\_\_\_\_

13. What is your ethnicity?

- Hispanic or Latino
- Not Hispanic or Latino
- Mixed ethnicity
- Prefer not to answer
- Other \_\_\_\_\_

14. What made it hard for you to take part in a clinic trial and/or why have you not taken part in a trial (Check all that apply)?

- No reasons
- Doctor never told me about trials
- Too hard for me to travel to study site
- Study required too many additional trips to the hospital
- Trial was going to cost additional money that my insurance wouldn't cover

- I was concerned that I would need to pay additional money for non-medical expenses (i.e. not directly related to the trial such as travel, parking, hotel accommodations, child care, time off work, etc.)
- My surgery would be delayed if I took part in the study
- I was afraid that I would not get a real treatment like a sugar pill or fake medication
- I did not have any family or friends to help me
- I did not want a kidney biopsy (i.e. a needle put in my kidney to get a cancer diagnosis) so that I could take part in the trial?
- I was told that I didn't qualify for a study at this time/My doctor told me that I didn't qualify for any studies at this time
- I don't want to be part of an experiment
- Other \_\_\_\_\_

15. For the following questions, if a trial was offered before your kidney surgery, what would make it easier for you take part?

i. If I can be treated by my kidney cancer doctor that I have now

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

ii. If my surgery would not be delayed more than 2 weeks

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

iii. If my surgery would not be delayed more than 4 weeks

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

iv. If my extra expenses would be paid, such as child care, parking, time off work from appointments

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

v. If someone could help me organize scheduled appointments

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

vi. If I didn't have to get any extra tests performed (i.e. a kidney biopsy) in order to participate in the trial

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

vii. If I knew that I would receive a real drug that has helped patients or a new drug which will possibly help patients

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

viii. Other \_\_\_\_\_

16. What are the most important reasons to take part in a clinical trial?

i. To help prevent the return of cancer

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

ii. To help slow the return of cancer

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

iii. To help me live longer with the cancer

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

iv. To help scientist learn how the cancer acts to make better treatments

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

v. To help make the surgery easier and possibly remove less of my kidney

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

vi. To help with research for other patients in the future

- Highly important
- Somewhat important
- Somewhat unimportant
- Not important
- Unsure

vii. Other \_\_\_\_\_

17. While most trials include drugs that have been shown to improve your health or studying drugs that are thought to improve your health, occasionally, studies are designed where a patient may receive a sugar pill or fake medication. Would you participate in a clinical trial where you may receive a sugar pill or fake medication?

- Yes
- No, I would not participate in a trial where I could receive a sugar pill or fake medicine
- No, I would never be part of a clinical trial
- Maybe
- I Don't know

18. Would you participate in a clinical trial that required a kidney biopsy? You would have a mild pain killer while a small needle went into your kidney to get cancer tissue; this would tell the doctors about your cancer tumor?

- Yes
- No, I would not participate in a trial where that required a small needle placed in my kidney
- No, I would never be part of a clinical trial
- Maybe
- I Don't know

19. Would you take part in a clinical trial if it made it longer to get surgery?

- Yes
- No, I would not participate in a trial that made it longer to get surgery
- No, I would never be part of a clinical trial
- Maybe
- I Don't know

20. Would you take part in a clinical trial if it made you travel more than 50 miles to do so

- Yes
- No, I would not travel that far
- No, I would never take part in a clinical trial
- Maybe
- Don't know

21. Would you participate in a clinical trial that required you to make additional appointments to a medical clinic?

- Yes, if there were less than 3 extra appts
- Yes, if there were less than 5 extra appts

- Yes, if there were less than 10 extra appointments
- Yes, no matter the number of extra appointments
- No, I would not want to participate if there were any additional medical appointments required
- Maybe
- I don't know

22. What would help you decide to take part in a trial (Check all that apply)?

- Talk directly with my doctor
- Talk directly with the nurse or other medical person, that is not my cancer doctor
- Talk directly to a person from the research study team, that is not my doctor or nurse
- Read print outs that I can read at home before I decide
- Get a video that I can watch at home
- Have telephone or website support person to ask questions
- Other \_\_\_\_\_

Appendix B: Sensitivity analysis for importance questions

<b>Reasons to Participate in a Clinical Trial</b>			
<b>Highly Important Order</b>		<b>Important (Highly Important + Somewhat Important) Order</b>	
Prevent Cancer return	71 (76%)	Prevent Cancer return	75 (80%)
Help me live longer	70 (74%)	Help me live longer	72 (77%)
Slow Cancer return	66 (70%)	Help scientist make better treatments	70 (74%)
Help scientist make better treatments	60 (64%)	Help with research for future patients	70 (74%)
Help make surgery easier and remove less kidney	56 (60%)	Slow Cancer return	69 (73%)
Help with research for future patients	50 (53%)	Help make surgery easier and remove less kidney	68 (72%)

<b>What would make clinical trial participation easier?</b>					
<b>Highly Important Order</b>			<b>Important (Highly Important + Somewhat Important) Order</b>		
	n (%)	p		n (%)	p
No placebo	45 (48%)		No placebo	63 (67%)	
Surgical Delays		0.57	Surgical Delays		0.78
Surgery not delayed > 4 weeks	36 (38%)		Surgery not delayed > 4 weeks	52 (55%)	
Surgery not delayed > 2 weeks	32 (34%)		Surgery not delayed > 2 weeks	50 (53%)	
Extra expenses paid	31 (33%)		Extra expenses paid	49 (52%)	
Treated but current oncologist	29 (31%)		Treated but current oncologist	48 (51%)	
No extra tests	19 (20%)		Help with organizing scheduled appointments	33 (35%)	
Help with organizing scheduled appointments	18 (19%)		No extra tests	33 (35%)	