Appendix 1

**Patient Survey questions:**

Basic Demographics

* What is your age (years)?
  + free response
* What is your ethnicity?
  + Hispanic or Latino, not Hispanic or Latino, Unknown, Don’t want to answer
* What is your race?
  + American Indian/Alaska Native, Asian, Native Hawaiian or other pacific islander, black or African American, White, more than one race, unknown, Don’t want to answer
* What is your gender?
  + male, female, Don’t want to answer
* What is your highest education level?
  + less than 12 years, high school graduate, some college/university, technical or trade school, college graduate, post graduate degree, other please specify, Don’t want to answer
* What is your current marital status?
  + single never married, married, divorced, widowed, separated, Don’t want to answer
* What are your current living arrangements?
  + live alone, live with others, Don’t want to answer
    - if select ‘live with others’…who do you live with?
      * free response
* What is your current employment status?
  + employed full time, employed part time, retired, homemaker, unemployed seeking work, unemployed not seeking work, other please specify, Don’t want to answer
* What is your current household income per year? (please include income from yourself, your partner or spouse and others you regard as family living in your household)
  + Less than $9,275; $9,276-$37,650; $37,651-$91,150; $91,151-190,150; More than 190,151; Unsure; Other please specify, Don’t want to answer
* Do you have a family history of cancer?
  + Yes, no, unsure, Don’t want to answer
    - if select ‘yes,’…who in your family has been diagnosed with cancer?
      * Grandparent(s), mother, father, sibling(s), child or children, other please specify, Don’t want to answer
    - If select ‘yes’…what type of cancer was your family member(s) diagnosed with?
      * Breast, lung, prostate, colorectal, kidney, melanoma, other please specify, Don’t want to answer
* Do you have a family history of kidney disease?
  + Yes, no, unsure, Don’t want to answer
    - if select ‘yes,’…who in your family has been diagnosed with kidney disease?
      * Grandparent(s), mother, father, sibling(s), child or children, other please specify, Don’t want to answer
    - If select ‘yes’…what type of kidney disease has your family member(s) been diagnosed with?
      * Free response
    - If select ‘yes’…has your family member(s) required any of the following?
      * Dialysis, transplant, other please specify, Don’t want to answer
* Have you ever been told by a doctor that you have a renal (kidney) cyst?
  + Yes or no
    - if select ‘no,’…Imagine you’ve been told by a doctor that you have a renal cyst. Please respond to the following questions.

Values and preferences

~Overall health

* In general, would you say your overall health, on most days, is:
  + excellent, very good, good, fair, poor, Don’t want to answer
    - if select ‘fair’ or ‘poor’…is your current health condition related to:
      * kidney problems, cancer, other (please specify), Don’t want to answer
* Do you currently have health insurance?
  + Yes, no, unsure, Don’t want to answer
    - if select ‘yes’…does your insurance cover imaging services?
      * Yes, no, unsure, Don’t want to answer
        + If select ‘yes’…what is your approximate health insurance copay?

Less than $20, $20-$50, more than $50, Unsure, Don’t want to answer

* How often do you discuss the cost of follow-up imaging or the cost of other treatments regarding renal cysts with your doctor?
  + always, almost always, sometimes, rarely, never, unsure, Don’t want to answer
* Have you ever been told by a doctor that you have diabetes?
  + Yes, no, unsure, Don’t want to answer
* Have you ever been told by a doctor that you have high blood pressure?
  + Yes, no, unsure, Don’t want to answer
* Have you ever been told by a doctor that you have heart disease?
  + Yes, no, unsure, Don’t want to answer
* Have you ever been told by a doctor that you have any other conditions?
  + Yes, no, unsure, Don’t want to answer
    - If select ‘yes’…please specify
      * free response

~We’d like to hear about your experience or opinion about renal cysts and their follow-up

* When did you first find out you had a renal cyst?
  + Less than 1 year ago, 1-3 years ago, 3-5 years ago, more than 5 years ago, no renal cyst, unsure, Don’t want to answer
* How many renal cysts have you had?
  + 0, 1, 2-4, more than 4, unsure, Don’t want to answer
    - If select 1, 2-4, or more than 4…is your renal cyst(s) in:
      * one kidney, both kidneys, Don’t want to answer
    - If select 1, 2-4, or more than 4….what is the approximate size(s) of your renal cyst(s)
      * Less than 5mm, 5-10mm, 10mm-1cm, 1cm-3cm, larger than 3cm, unsure, other please specify, Don’t want to answer
* Do you have a specific treatment or follow-up plan for your renal cyst?
  + Yes, no, no renal cyst, Don’t want to answer
    - if ‘yes’…what treatment have you been offered?
      * repeat imaging, surgery, other (please specify), Don’t want to answer
        + if ‘repeat imaging’…how often do you have repeat imaging?

free response

* + - If select ‘yes’……do follow-up visits give you a sense of security?
      * Yes definitely, Yes, Yes somewhat, undecided, No somewhat, No, Definitely no, Don’t want to answer
        + Can you say more about this?

Free response

* + - If select ‘yes’…Are you nervous before a follow-up visit?
      * Yes definitely, Yes, Yes somewhat, undecided, No somewhat, No, Definitely no, Don’t want to answer
        + Can you say more about this?

Free response

* + - If select ‘yes’…Are you reassured after a follow-up visit?
      * Yes definitely, Yes, Yes somewhat, undecided, No somewhat, No, Definitely no, Don’t want to answer
        + Can you say more about this?

Free response

* + - If select ‘yes’…Would you worry more about the renal cyst(s) if there was not follow-up?
      * Yes definitely, Yes, Yes somewhat, undecided, No somewhat, No, Definitely no, Don’t want to answer
        + Can you say more about this?

Free response

* Are you satisfied with the management plan (or lack of a management plan) for your renal cyst(s)?
  + Very satisfied, satisfied, somewhat satisfied, neutral, somewhat dissatisfied, dissatisfied, very dissatisfied, no renal cyst, Don’t want to answer
    - Can you say more about this?
      * Free response
* Do renal cysts affect your day to day life?
  + Yes, no, unsure, Don’t want to answer
    - If ‘yes’…Can you say more about this?
      * Free response

~Knowledge, education, and support

* Do you have important questions to ask a doctor about renal cysts?
  + Yes, no, unsure, Don’t want to answer
    - If ‘yes’…Do you agree or disagree with this statement: when I have important questions to ask a doctor about renal cysts, I get answers I can understand.
      * strongly agree, agree, agree somewhat, undecided, disagree somewhat, disagree, strongly disagree, Don’t want to answer
* Do you agree or disagree with this statement: I feel fully informed about renal cysts and the risk of progression.
  + strongly agree, agree, agree somewhat, undecided, disagree somewhat, disagree, strongly disagree, Don’t want to answer
* In your opinion, what is the risk of progression to cancer for a renal cyst?
  + Very high risk, high risk, some risk, low risk, very low risk, no risk, undecided, Don’t want to answer
    - What sources informed your opinion on this?
      * Doctor, Family, Friends, Internet, No sources, Other: Free response, Don’t want to answer
* How easy or hard is it to understand the risk of renal cyst progression?
  + very easy, easy, somewhat easy, undecided, somewhat hard, hard, very hard, Don’t want to answer
* Do you agree or disagree with this statement: I am anxious about my renal cyst(s).
  + strongly agree, agree, agree somewhat, undecided, disagree somewhat, disagree, strongly disagree, no renal cyst, Don’t want to answer
    - Can you say more about this?
      * Free response
* Is the doctor you see about your renal cyst(s) your primary care physician?
  + Yes, no, no renal cyst, Don’t want to answer
* Is the doctor you see about your renal cyst(s) a nephrologist or urologist?
  + Yes, no, no renal cyst, Don’t want to answer
* Do you see someone else about your renal cyst(s)?
  + Yes, no, no renal cyst, Don’t want to answer
    - If select ‘yes’…please specify
* Is there anyone else involved in your care?
  + Family member(s), in home healthcare, no one, other please specify, Don’t want to answer
* Do you agree or disagree with this statement: My doctor considers my values and opinions regarding follow-up imaging for my renal cyst(s).
  + strongly agree, agree, agree somewhat, undecided, disagree somewhat, disagree, strongly disagree, no renal cyst, Don’t want to answer
* Do you want to be more involved in decisions made about your care and treatment?
  + Yes definitely, yes to some extent, no, Don’t want to answer
* Is there other information that you would like to know about renal cysts?
  + Yes, no, unsure, Don’t want to answer
    - if ‘yes’…please specify:
      * free response
* Would you like to receive more information about renal cysts?
  + Yes, no, unsure, Don’t want to answer
    - If select ‘yes’...is there specific information you would like to receive?
      * Free response
* Is there anything else you would like us to know about your values and preferences regarding renal cysts and their follow-up?
  + Free response

Appendix 2: STROBE Statement—checklist of items that should be included in reports of observational studies

|  |  |  |  |
| --- | --- | --- | --- |
|  | Item No | Recommendation | Page  No |
| **Title and abstract** | 1 | (*a*) Indicate the study’s design with a commonly used term in the title or the abstract | 2 |
| (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | 2 |
| Introduction | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | 4 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | 4-5 |
| Methods | | | |
| Study design | 4 | Present key elements of study design early in the paper | 5 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 5-6 |
| Participants | 6 | (*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up  *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls  *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants | 5-6 |
| (*b*)*Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed  *Case-control study*—For matched studies, give matching criteria and the number of controls per case |  |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 6 |
| Data sources/ measurement | 8\* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | 6 |
| Bias | 9 | Describe any efforts to address potential sources of bias | 6-7 |
| Study size | 10 | Explain how the study size was arrived at | Not applicable – included all subjects with a response |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | 6 |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | 6 |
| (*b*) Describe any methods used to examine subgroups and interactions | 6 |
| (*c*) Explain how missing data were addressed | Not applicable – included all subjects with a response |
| (*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed  *Case-control study*—If applicable, explain how matching of cases and controls was addressed  *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy | Not applicable |
| (*e*) Describe any sensitivity analyses | Not applicable |

|  |  |  |  |
| --- | --- | --- | --- |
| Results | | | |
| Participants | 13\* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | 7 |
| (b) Give reasons for non-participation at each stage | Not applicable |
| (c) Consider use of a flow diagram | Not applicable |
| Descriptive data | 14\* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | 7 |
| (b) Indicate number of participants with missing data for each variable of interest | 7 |
| (c) *Cohort study*—Summarise follow-up time (eg, average and total amount) | Not applicable |
| Outcome data | 15\* | *Cohort study*—Report numbers of outcome events or summary measures over time |  |
| *Case-control study—*Report numbers in each exposure category, or summary measures of exposure |  |
| *Cross-sectional study—*Report numbers of outcome events or summary measures | 7-8 |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | 7-11 |
| (*b*) Report category boundaries when continuous variables were categorized | 7-11 |
| (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | Not applicable |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | Not applicable |
| Discussion | | | |
| Key results | 18 | Summarise key results with reference to study objectives | 11 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | 12 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | 12 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | 12-13 |
| Other information | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 3 |