KidsCanSeq Oncologist Follow-Up Survey (IRB approved 8-21-2018)

We appreciate your continued participation in the **KidsCanSeq Study**. The purpose of this survey is to understand oncologists' opinions and perceptions of the utility of genomic sequencing after some time in the study and experience with the study results.

As a reminder, in the KidsCanSeq Study, we utilized a combination of clinical sequencing tests to identify inherited mutations and tumor mutations in children with central nervous system (CNS) and non-CNS solid tumors and lymphomas. The **TUMOR** tests that are performed for KidsCanSeq study patients (if tumor sample is sufficient) are (1) Pediatric Solid Tumor Comprehensive Panel (mutation panel, fusion panel) and (2) Cancer Genome Profile (exome sequencing, RNA sequencing, and copy number array). The **GERMLINE** tests that are performed for KidsCanSeq study patients are (1) Pediatric Solid Tumor Mutation Panel and (2) Whole Exome Sequencing. **Throughout this survey, we refer to these tests collectively as "genetic testing" and specify between testing of tumor and germline where necessary.** Not all patients received all of these types of genetic testing.

In this survey, we will ask you questions about your attitudes toward genetic testing and your experience in the KidsCanSeq Study. This survey should take about 20 minutes to complete.

Thank you for your participation in the KidsCanSeq Study.

[PRG: don't show question numbers in survey]

First, we would like to ask about your experience participating in the KidsCanSeq Study.

1. **Overall, how satisfied were you with your experience in the KidsCanSeq Study?**
   - Very dissatisfied
   - Dissatisfied
   - Satisfied
   - Very satisfied

2. **What do you think worked well in the KidsCanSeq Study?** [PRG: FREE TEXT BOX]

3. **What would you recommend improving about the KidsCanSeq Study?** [PRG: FREE TEXT BOX]

4. **How interested are you in integrating these types of genetic testing into the clinical care of your patients?**

	Not at all interested	**Slightly Interested**	**Interested**	**Very interested**
Germline genetic testing	○	○	○	○
Tumor genetic testing	○	○	○	○

Next, we'll ask you some questions about what you think about genetic testing.

5. **How confident are you in your ability to…**

	Not at All Confident	**Not Very Confident**	**Somewhat Confident**	**Very Confident**
Explain the germline result to your patient?	○	○	○	○
Explain the tumor result to your patient?	○	○	○	○
Answer your patient's questions about the germline result?	○	○	○	○
Answer your patient's questions about the tumor result?	○	○	○	○
Manage your patient's care based on the germline result?	○	○	○	○
Manage your patient's care based on the tumor result?	○	○	○	○

6. On a scale of 1 to 5, how useful do you think the results from each of the following types of testing were in the clinical management of your patients?

	Not at all Useful (1)	2	3	4	Extremely Useful (5)
Targeted gene panel (tumor)	○	○	○	○	○
Integrated genomic profiling (tumor)	○	○	○	○	○
Targeted gene panel (germline)	○	○	○	○	○
Whole exome sequencing (germline)	○	○	○	○	○

On the scale below, please rate how much you agree or disagree.

I think <u>germline</u> genetic testing was useful to:

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
7. Help guide decision-making for my patients' cancer care at time of diagnosis	○	○	○	○	○
8. Help guide decision-making for my patients' cancer care in the event of recurrence	○	○	○	○	○
9. Identify a cause for my patients' cancers	○	○	○	○	○
10. Accurately characterize my patients' risk for disease(s) other than their current cancer diagnosis	○	○	○	○	○
11. Influence what treatment my patients receive for future medical problems not related to cancer	○	○	○	○	○
12. Influence what non-cancer medications my patients take	○	○	○	○	○
13. Influence my patients' future reproductive decisions	○	○	○	○	○
14. Lead my patients' parents to undergo genetic testing or cancer screening	○	○	○	○	○
15. Lead my patients' family members to undergo genetic testing or cancer screening	○	○	○	○	○
16. Provide my patients' parents with information they want	○	○	○	○	○

17. Provide my patients' parents with peace of mind	○	○	○	○	○
18. Relieve my patients' parents from guilt about the possibility that they passed on a gene that contributed to their child getting cancer	○	○	○	○	○
19. Relieve my patients' parents from guilt about something they may have done or not done that contributed to their child getting cancer (other than passing on a gene)	○	○	○	○	○
20. Enable my patients' parents to plan more effectively for the future	○	○	○	○	○
21. Influence my patients' parents' reproductive decisions	○	○	○	○	○

On the scale below, please rate how much you agree or disagree.

I think <u>tumor</u> genetic testing was useful to:

	Strongly Disagree	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
22. Help guide decision-making for my patients' cancer care at time of diagnosis	○	○	○	○	○
23. Help guide decision-making for my patients' cancer care in the event of recurrence	○	○	○	○	○
24. Identify a cause for my patients' cancers	○	○	○	○	○
25. Provide my patients' parents with information they want	○	○	○	○	○
26. Provide my patients' parents with peace of mind	○	○	○	○	○
27. Enable my patients' parents to plan more effectively for the future	○	○	○	○	○

28. How useful did you find these KidsCanSeq study resources?

	Not at all useful	Somewhat useful	Useful	Very useful
Emails from study team to interpret germline testing results	○	○	○	○
Emails from study team to interpret tumor testing results	○	○	○	○
Genetic counselors providing germline results to families support	○	○	○	○
Other Germline team support	○	○	○	○
Other Tumor team support	○	○	○	○

29. As genomic medicine is integrated into clinical care at your institution, what level of genetic resources do you think would be necessary?

	Not necessary	Low priority	Medium priority	High priority	Essential
Interpretive services for germline testing results	○	○	○	○	○
Interpretive services for tumor testing results	○	○	○	○	○
Genetic consult services	○	○	○	○	○
Precision oncology consult services	○	○	○	○	○
Genetic counseling services	○		○	○	○

30. What do you think worked well about the genetic resources available in the KidsCanSeq study? [PRG: FREE TEXT BOX]

31. What would you recommend improving about the genetic resources available in the KidsCanSeq study? [PRG: FREE TEXT BOX]

In our previous BASIC3 study, which some of you participated in, oncologists and the study genetic counselors returned the germline and tumor results to families together in one disclosure. In the KidsCanSeq study the study genetic counselor is giving back the germline testing results with significant findings and oncologists' participation is optional. Of note, if results are non-significant there is no disclosure and results are returned via letter).

32. **Would you have preferred to participate in all germline testing results disclosures with significant findings?**
    - ○ Yes [PRG: If selected, ask: **In what ways?** FREE TEXT BOX]
    - ○ No

    If you participated in the BASIC3 study, how did this change to study procedures compare to your previous experience? [PRG: FREE TEXT BOX]

33. **Did you use any resources to help you interpret the sequencing report(s) you received? Please select all that apply.**
    - ☐ Genetics Home Reference
    - ☐ Online Mendelian Inheritance in Man (OMIM)
    - ☐ GeneReviews
    - ☐ Literature search (PubMed, Ovid)
    - ☐ Google, Bing, Yahoo, or other search engines
    - ☐ Discussions with physician(s) or genetic counselor(s) within the KidCanSeq Project
    - ☐ Discussions with colleague(s) or specialist(s) outside of the KidsCanSeq Project
    - ☐ Other, please specify: [PRG: FREE TEXT BOX]
    - ☐ I did not use any additional resources [PRG: if selected, don't allow selection of other response options]

34. **We know it depends on the patient, but at what age do you typically start engaging your patients in discussions about whether to undergo genetic testing or receiving results?** [PRG: Drop down, <6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18]

    [PRG: if select anything except "18" above, ask:] **Please describe how you engage your patients who are under 18 years old in these discussions:** [PRG: FREE TEXT BOX]

Now, we would like to ask you what you think about integrating genomic medicine into your clinical care setting.

35. **Overall, my institution is prepared to integrate genomic medicine into clinical care.**
    - ○ Strongly Disagree
    - ○ Disagree
    - ○ Neither Agree nor Disagree
    - ○ Agree
    - ○ Strongly Agree

36. **Please describe the ways in which your institution is prepared and/or is not prepared to integrate genomic medicine into clinical care:** [PRG: FREE TEXT BOX]

Now, please think about all of the clinical encounters in which an interpreter of any language may have helped you communicate genetic testing information to families. “Families” refers to pediatric cancer patients, their parents, and any other relatives who may have been present during the encounters. **Note that we are referring only to genetic testing encounters, *not* standard of care targeted genetic testing.**

37. **Did you use an interpreter in any clinical encounters (inside or outside of the KCS study) in the last year when you discussed genetic testing information with families of pediatric cancer patients?**
    - ○ Yes [PRG: if yes, show next Qs]
    - ○ No

In clinical encounters where an interpreter helped you communicate genetic testing information to families, please tell us how often you experienced the following:

	None of the time	Some of the time	Most of the time	All of the time
38. I was satisfied with the interpreters that helped me communicate genetic testing information to families [PRG: if select any:] Please describe any challenging or exemplary experiences: [PRG: FREE TEXT BOX]	○	○	○	○
39. Interpreters and I worked well together	○	○	○	○
40. Interpreters helped me notice when families had problems understanding the genetic testing information I presented.	○	○	○	○
41. Interpreters seemed knowledgeable about how to convey the genetic testing information I presented.	○	○	○	○
42. Interpreters asked me for clarification about the genetic testing information I presented.	○	○	○	○

You have reached the end of the survey. Please click the SUBMIT button below if you are happy with your answers. If you need to review or change any answers, click on the PREVIOUS button to go back.

[PRG: After Survey Submitted]: Thank you for participating in the KidsCanSeq Study and completing this survey!