EVALUATING UTILITY AND IMPROVING IMPLEMENTATION OF GENOMIC SEQUENCING FOR PEDIATRIC CANCER PATIENTS IN THE DIVERSE POPULATION AND HEALTHCARE SETTINGS OF TEXAS: The KidsCanSeq Study

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A. Background

Cancer is a genetic disease caused by the sequential accumulation of a diverse array of genetic alterations in oncogenes and tumor suppressor genes. The majority of these alterations are somatic (occurring in the tumor but not in the constitutional DNA) and will be referred to here as "tumor mutations," but a substantial minority of pediatric cancer patients (most commonly solid and brain tumor patients) also have germline or "inherited mutations" in cancer susceptibility genes. These inherited mutations significantly increase a patient's risk of developing additional cancers and have similar implications for family members who may carry the same genetic change. Thus, the identification of the specific tumor and inherited gene alterations has enabled both the development of improved risk prediction and cancer screening algorithms as well as the development of cancer therapeutic agents specifically targeting mutated genes or biological pathways. An increasing number of these "molecularly-targeted" cancer therapies have now entered early-phase (I/II) clinical trials for children with recurrent and refractory cancers. In contrast to children with newly-diagnosed cancers who are treated according to standardized treatment protocols, the prognoses for children with recurrent or progressive cancers after standard therapy are typically extremely poor (especially for patients with recurrent central nervous system (CNS) tumors and non-CNS solid tumors). Existing treatment options in the event of recurrent disease are unlikely to be curative, while treatment decisions are often varied, and may range from additional therapy with conventional modalities, enrollment on clinical trials utilizing novel therapeutic approaches, to comfort-directed care without further specific anticancer therapy.

Recent development and proliferation of clinically-available genomic sequencing technologies have enabled the systemic examination of alterations occurring in germline DNA as well as in tumor DNA and RNA, in CAP and CLIA-certified laboratories. In theory, these clinical genomic reports provide a biologic rationale for personalized cancer care, with early examples reported for treatment of recurrent adult tumors. Prior research in the BASIC3 study helped provide early data on the impact of incorporating these genome-scale data into the clinical care of children with cancer and its effect on medical decisions at cancer relapse, and improved assessment of inherited cancer risk for the patient and family. With the proliferation of both targeted and genome-scale tests, research is necessary to directly compare the utility of available sequencing tests which range in scale and cost, to understand the capability of oncologists and cancer geneticists to interpret these complex data, how often results for a child with cancer impact close relatives and to identify best strategies to explain results to parents (physician-parent communication) and determine parental understanding of germline results related to the child's cancer diagnosis or other conditions that are identified incidentally.

B. Purpose and Objectives

The primary goal of KidsCanSeq is to compare the clinical utility of a targeted gene panel designed for tumor evaluation versus more extensive germline and tumor genomic

sequencing, for the care of childhood cancer patients with solid tumors, lymphomas, and rare histiocytic disorders in diverse clinical settings. We propose to assess the clinical utility of tumor sequencing data through direct comparison of different sequencing tests, using pre-specified definitions of actionability, to address questions including:

- Does more extensive genome-scale testing increase the diagnostic yield of actionable tumor and inherited alterations (compared with a targeted pediatric cancer gene panel) for children with these tumor types?
- Is there a difference in the frequency of actionable tumor mutations between Hispanic and non-Hispanic children with these tumor types?
- What fraction of the cancer gene mutations detected in high-risk tumors by a targeted pediatric cancer gene panel represent germline as opposed to somatic events?
- How often is genetic testing recommended (and undertaken) by siblings and parents based on the results of genetic testing in the child?

We will follow patients for two years after enrollment and assess the impact of the various genetic tests on clinical decision making by studying physician and patient-centered outcomes.

In addition to generating important data on the clinical utility of these genetic testing modalities for pediatric cancer care, this project will provide the clinical framework for the examination of ethical and psychosocial implications of such an approach.

Additional exploratory goals of this study are to evaluate technologic, bioinformatics, health economic, and cultural barriers to advancing clinical genomic and precision oncology strategies to the care of children with cancer. Planned pilot projects include: assessment of whole genome sequencing as an alternative test, a health economic assessment and comparison of the clinical tests used in the study, and incorporation of clinician decision support tools related to genomic results in the electronic health record.

Specific Aims

Aim 1. Compare the clinical utility of a targeted gene panel designed for tumor evaluation versus more extensive germline and tumor genomic sequencing in the care of childhood cancer patients.

A. Tumor analysis. Compare the frequency of actionable tumor findings and effect on treatment decisions of the targeted panel (DNA/RNA) versus whole exome sequencing (WES), transcriptome sequencing, and copy number array of FFPE tumor samples from the subset of study patients with high-risk tumors (n=270 sequenced).

B. Germline analysis. Compare the frequency of diagnostic and/or actionable germline findings from the same targeted panel versus WES from a cohort of children with unselected central nervous system (CNS) and non-CNS solid tumors or lymphomas (n=825 sequenced).

Aim 2. Explore the impact of diagnostic and/or actionable germline findings on genetic testing decisions and healthcare utilization of first degree relatives across the study populations.

A. Familial genetic testing. Assess how often first degree relatives of probands with diagnostic and/or actionable germline findings undergo genetic testing and assess differences between populations (in particular Hispanic and non-Hispanic) with regard to accessibility and willingness to undergo testing.

B. Familial testing preferences and access to cancer surveillance. Assess differences between populations (in particular Hispanic and non-Hispanic) with regard to uptake of recommended surveillance, availability of services, and other obstacles to obtaining care for relatives who test positive for the genetic findings.

Aim 3. Evaluate the perceived utility of genome sequencing in the care of childhood cancer patients from the perspective of a diverse group of parents and clinicians.

A. Parental perceived utility. Determine parents' expectations and experiences of the utility of genomic sequencing across the diverse patient populations of Texas.

B. Oncologist perceived utility. Determine oncologists' expectations and experiences of the utility of genomic sequencing across diverse healthcare settings in Texas.

Aim 4. Develop, implement, and evaluate novel, culturally sensitive methods for consent and communicating of complex genomic information in a clinical genomics trial.

A. Educational materials. Develop and assess educational videos to provide consistent culturally-sensitive messaging as a component of clinical genomics consent across diverse populations.

B. Communicating germline results. Evaluate barriers to effective communication of genomic information including visit modalities (face-to-face vs. telemedicine) and language context.

C. Clinical reporting. Develop and optimize through stakeholder feedback standardized germline exome counseling letters in English and Spanish.

Aim 5. Implement pilot projects to advance the field of genomic medicine in pediatric oncology.

A. Health economics. Compare the costs of identifying tumor actionable mutations via a targeted cancer gene panel as compared to more extensive genomic test modalities.

B. Electronic Health Record (EHR). Create a clinician decision support tool in the electronic health record (EHR) at Texas Children's Hospital to facilitate timely compliance with cancer surveillance recommendations.

C. Whole genome sequencing (WGS). Perform WGS on matched FFPE tumor, frozen tumor, and blood samples of a cohort of BASIC3 patients (n=50) to develop an analytic and clinical reporting pipeline.

D. Circulating tumor DNA analysis (ctDNA). Explore approaches to diagnosing and profiling genomics of pediatric cancers through evaluation of ctDNA.

C. Design/Procedure

C1. Selection criteria

Inclusion Criteria:

- Children less than 18 years of age with newly-diagnosed or recurrent solid tumors (CNS and non-CNS), lymphomas, and rare histiocytic disorders who plan to receive primary longitudinal oncology care at a Texas KidsCanSeq institution.
- Parents of KidsCanSeq study patients
- Primary pediatric oncologists of KidsCanSeq study patients at the participating sites.

Exclusion Criteria:

- Subjects without at least one parent who speaks either English or Spanish
- Subjects diagnosed with benign non-CNS solid tumors, e.g. neurofibroma.
- Subjects with a history of prior allogeneic bone marrow or stem cell transplant

C2. Procedure

A. Overall study plan. Clinical germline (blood) sequencing will be performed on all enrolled patients. Tumor sequencing will only be performed on a subset of patients with treatment-refractory or recurrent tumors, or high-risk newly-diagnosed tumors (Appendix A).

1. **Informed consent and study enrollment.** Please see section G (consent procedures) for a detailed description of the plan for obtaining informed consent from study subjects (patients, parents, and oncologists).

2. **Collection and shipment of patient study samples.** Patient tumor (if available),blood, and/or saliva samples will be collected and sent from each site to Texas Children's Hospital (TCH) for tumor and germline testing in CAP/CLIA-certified laboratories. Note, some of the same clinical genetic tests that are planned as part of this study may have previously been ordered by the subject's physician as part of their routine medical care. If such tests have already been completed, we will review whether those results can be used as part of this study and not repeat the test(s) unless there is a specific reason to do so (such as if the test was performed a long time ago or the test methods have been updated).

    A. **Tumor samples.** Tumor samples utilized for study purposes will have been collected during medically-indicated procedures, after a sufficient amount of material has been obtained for diagnostic pathological evaluation. Available samples (formalin-fixed paraffin-embedded, FFPE; or frozen) will be shipped to the TCH Molecular Pathology Laboratories (MPL) for sample processing, extraction of nucleic acids, and distribution of nucleic acids to the clinical laboratories performing the sequencing tests. Participating study sites will be provided the U01 study as a charge source for sample processing and shipping. Subjects will be given the option of allowing tumor samples to be similarly collected from future and previous medically-indicated cancer surgeries.

    B. **Blood samples**. Patient blood samples will be obtained either as an inpatient or an outpatient at the enrolling study site. When possible, additional venipuncture will be avoided by having blood samples drawn at the same time as other clinical tests are being ordered and/or obtaining the blood sample through the patient's central line. Subjects will be asked to donate 25 mL of blood (not to exceed 3 ml per kg of body weight per 24 hours). Blood samples will be sent to the TCH MPL for study procedures as described for tumor samples.

    C. **Saliva samples**. In cases where a blood sample cannot be obtained, patient saliva samples will be obtained either as an inpatient or an outpatient at the enrolling site. Saliva samples will be sent to the TCH MPL for study procedures as described for tumor samples.

    Note: If either a patient blood or saliva sample is not received within 2 months of study enrollment, the subject will be removed from the study.

3. **Collection and shipment of parental study samples**. Parental saliva samples will be collected from participating biological parents at the time of their enrollment. These

samples do not undergo WES but are utilized as part of the WES test of the child, to confirm the presence and inheritance pattern of germline variants identified in the patient. Both parents (if available) will be asked to enroll in KidsCanSeq and donate saliva to be sent to the TCH MPL for this purpose. Saliva collection will be performed at the study sites or by providing parents with saliva collection kits that can be used at home and returned by mail. If additional parental germline DNA is needed for study purposes, parents may be asked to provide a blood sample (25 mL), which will be collected at the study site. Additional genetic studies, including exome sequencing, may be performed on their samples on a research basis.

4. **Sequencing in CLIA-certified TCH/BCM laboratories.** Clinical sequencing of DNA/RNA from tumor samples and DNA from blood samples will be performed in the TCH MPL, the Baylor College of Medicine (BCM) Human Genome Sequencing Center-Clinical Laboratory (HGSC-CL), and the Baylor Genetics Laboratories (BGL). Four separate genetic reports (germline whole exome sequencing report, germline mutation panel report, tumor mutation panel report, and integrated tumor report [combining tumor whole exome sequencing, transcriptome sequencing, and copy number array]) will be generated as per standard laboratory procedures, incorporated into the electronic health record (EHR) of the participating institution, and shared with each patient's primary oncologist by study investigators (see below). A description of the information provided in the reports is also described below.

5. **Additional research genetic studies.** Different research tests will be done using the tumor and blood samples in order to comprehensively characterize the germline and tumor genetic alterations in children with CNS and non-CNS tumors, lymphomas, and rare histiocytic disorders. These tests will include studies of the extracted DNA, RNA, and proteins contained in these samples, such as targeted PCR amplification and sequencing of selected DNA and/or RNA fragments in tumors and blood; genome-wide sequencing of DNA and/or RNA; and sequence comparison against the patient blood sample and against human SNP and genome draft sequences available in the public databases. In addition, there may also be endeavors to make permanent cell lines or xenografts (methods of maintaining the growth of identical cells in the laboratory for an indefinite period of time) from these samples.

   The initial patient blood samples obtained after study enrollment will be analyzed for the presence of circulating tumor DNA. Longitudinal blood samples will also be collected from selected consenting patients (as an opt-in study procedure) approximately every 3-6 months, including at times of key clinical events such as surgical procedures, completion of treatment phases (radiation, chemotherapy), and disease progression or relapse. These longitudinally-collected samples will be used for pilot studies analyzing the utility of ctDNA for detection of clinically-relevant genetic alterations. The blood sample volume will be

approximately 20 mL (not to exceed 3 mL per kg of body weight per 24 hours). All attempts will be made to collect these samples at the time of other scheduled clinical blood draws.

6. Reporting of Genetic Testing Results.

1. Inherited mutation reports.

Inherited mutation reports (both mutation panel and exome) will be generated and reported according to the BGL's standard clinical procedures. All reports are reviewed and signed by American Board of Medical Genetics or American Board of Pathology - Molecular Diagnostic-certified laboratory directors. These inherited mutation reports will be annotated following recent clinical classification guidelines from the American College of Medical Genetics and Genomics/Association for Molecular Pathology and include information such as whether the variant is pathogenic, likely pathogenic or variant of uncertain significance. Benign or likely benign results are generally not reported. The reports will be sent to the KidsCanSeq site that ordered the test. In addition to being shared with the patient's oncologist and parents, this clinical report will be included in the EHR. If parental samples have been provided, the report also states whether a parent carries this mutation or if it appears to be de novo in the child. The inherited mutation reports will be returned approximately 3 months after sample receipt and will include variants detected in the following categories:

i. Pathogenic variants in disease genes related to patient phenotype (cancer or other diseases)
ii. Variants of unknown clinical significance in disease genes related to phenotype
iii. Carrier status for pathogenic variants in 11 genes associated with recessive disease (example: *CFTR* pathogenic variant known to cause cystic fibrosis)
iv. Medically actionable pathogenic variants in disease genes unrelated to patient phenotype (example: pathogenic variant in *FBN1*, associated with Marfan syndrome and risk of aortic aneurysm for which there is recommended surveillance and treatment). Parents will be provided the option to opt out of this category of secondary findings at the time of study enrollment.

2. Tumor mutation reports.

Tumor mutation reports (both mutation panel and integrated tumor report) will be generated and reported according to the TCH MPL's standard clinical procedures. All reports are reviewed and signed by AMP/ABMG-certified laboratory directors. The reports will be sent to the KidsCanSeq site that ordered the test. In addition to being shared with the patient's oncologist, this clinical report will be included in the EHR. The tumor mutation panel report will be returned within approximately two weeks of sample receipt. The integrated tumor report (which includes combined analysis by whole exome sequencing, copy number array,

and transcriptome sequencing) will be provided in approximately 3 months. These tumor reports will be annotated following recent clinical classification guidelines from the Association for Molecular Pathology and include information such as: (1) whether there is a known investigational or FDA-approved drug which specifically targets this mutated gene, (2) whether the mutated gene is a member of a core cancer pathway, (3) whether the gene and/or specific mutation has previously been reported as mutated in the Catalogue of Tumor Mutations in Cancer (COSMIC) database and (4) whether the presence of this mutation is frequently or rarely seen in this tumor type.

7. **Sharing of genetic data with oncologists and families.** After the tumor mutation panel report, integrated tumor report, or the inherited mutation report for a patient has been incorporated into the EHR and returned to the patient's primary oncologist and the lead study oncologist at each site, the primary oncologist will be given the opportunity to discuss these results in person, by teleconference, or by email with the study principal investigators Dr. Plon (inherited mutation reports) and Dr. Parsons (tumor mutation reports) or other qualified members of the study team. These reports will be received at the different time points described above. The primary oncologist will share the tumor reports with the patient's family as a part of their child's clinical care as is routine for other types of tumor testing. A guide, "Guide to Interpreting Genomic Reports: A Genomics Toolkit", which describes the different types of results found in germline WES reports will also be made available to the oncologists at the following link: http://www.ashg.org/education/csertoolkit/index.html. The oncologists will be informed of this resource during the study education session provided at the time of their study enrollment.

   For the patients with negative germline reports (estimated to be approximately 85% of subjects - defined as no diagnostic, medically actionable or recessive pathogenic or likely pathogenic results), the site project coordinator (PC) will provide parents and/or patients who have reached the age of majority with a packet that includes (1) copies of the targeted panel and WES reports and (2) a genetic counseling letter explaining the testing and significance of a negative result in the patient's native language (English or Spanish). For the first 25 such cases a study GC will contact the parents 1-2 weeks following result receipt in order to assess understanding and satisfaction. If no significant concerns are raised, the remaining KidsCanSeq study families with negative germline reports will receive their child's germline testing results following the same procedure. All families receiving a negative result letter will be provided the option to contact a study GC telephone hotline with any additional questions. The frequency of use and questions posed will be tracked. The counseling letters will be modified as needed to address recurrent questions fielded over the course of the study.

   For patients with a positive diagnostic, incidental, or carrier status finding, the parents or patient who has reached the age of majority will be contacted by the PC to schedule a

return of results visit with a study GC. Due to the significant time interval between the informed consent discussion and results discussion, when the PC contacts the family to schedule return of results, the PC will encourage the family to watch the educational video again located on the study website and provide again the one page summary of potential types of results used during consent either by mail or electronically per the parent's preference.

If an on-site GC is available at that study location, the family can choose to have their results disclosure either in person visit or via teleconference appointment. Family preferences will be tracked. At sites without an on-site GC, the PC will schedule a teleconference appointment with the parents or the patient who has reached the age of majority. Zoom, a secure, encrypted, HIPAA compliant teleconferencing platform with which BCM has extensive experience, will be utilized for teleconferences. Parents will be sent an electronic invitation via email to connect to the teleconference. Parents will be able to connect via desktop, laptop, or mobile device. A Zoom connection will be made available at each study site for families who are unable to connect by other means. We will track the mode of connection used. In-person meetings and teleconferences will include the study GC and at least one parent. The GC will take relevant family history, review test results, provide supportive counseling, and recommend and discuss genetic testing options for other family members. For any tests where genetic testing is recommended for relatives due to diagnostic or actionable secondary findings, a letter describing the results and options for clinical testing will be provided to the parent or patient. We will follow-up at six months (to be consistent with the other sites in the CSER Consortium)with regard to siblings or parents who underwent genetic testing. For adult siblings, we will provide a release of information form. Family address(es) will be confirmed at the time of result visit and results will be mailed following disclosure. Interpreter services will be utilized for Spanish-speaking participants. In-person and videoconferences will be audio-recorded.

For patients who are lost to follow-up for any reason (including deceased patients) before the disclosure of positive genetic results, we will follow the following procedures:

(1) Study staff will make three attempts to contact the family by phone and/or email and one attempt by postal mail to schedule the disclosure.

(2) If unsuccessful, we will send a certified letter stating that the genetic test results have been completed and have been shared with the patient's oncologist and placed in the patient's EHR. The letter will specify how to contact study staff to arrange a follow-up appointment for return of results if desired by the family and will offer to mail the results along with a counseling letter to a local physician of their choice.

(3) Parents of deceased patients will have the option to review the results with appropriate study team staff (oncologist, geneticist, and/or genetic counselor) as well as

their primary oncologist in the manner of their choosing - either in person, by teleconference, or by telephone. These encounters will not be audio recorded.

8. Assessment of WES result communication and evaluation of oncologists' and parents' perceived utility of genome sequencing in the care of childhood cancer patients.

A. Evaluation of Communication in Positive Germline Result Disclosure Sessions. We will audio record a subset of the disclosure sessions in which any positive germline findings are returned to families. Information about audio recording of these sessions will be provided to parents at the time of consent for the study. The recordings will be professionally transcribed for content analysis, including (1) the communication between the genetic counselor and parent when disclosing genomic test results and (2) accuracy of interpretation of genomic information in sessions in which an interpreter is used will be performed using transcripts of the audio recordings. These recordings will continue until no new information is being revealed (i.e., saturation).

B. Oncologist Surveys. Participating oncologists from all study sites will be asked to complete two different types of electronic surveys. First, we will conduct a longitudinal cohort descriptive study of oncologists' self-reported expectations and perceived clinical utility of WES. These longitudinal surveys will be administered at two time points: (1) after study orientation and before any meetings with parents to return tumor results (baseline), and (2) one year prior to the end of study, after they have enrolled at least one patient. The surveys will collect information on age, gender, race/ethnicity, years of practice, and experience with genetics, and also assess oncologists' perceived utility of genomic sequencing. See Appendix B for the baseline oncologist survey and Appendix C for the end of study oncologist survey.

Second, the oncologists will be asked to respond to a brief patient-specific electronic survey each time they receive either a germline report or a tumor report containing a positive result, (i.e. a tumor report with a potentially-actionable mutation or a germline report with a pathogenic variant related to the development of the patient's phenotype or an actionable secondary finding), as well as for a subset of patients who receive germline reports containing no diagnostic or secondary results. The survey will be a brief post-disclosure checklist to document all clinical actions made based on the study results as well as the oncologist's perception of the clinical utility of those results. We will probe to assess which specific results prompted each clinical action. As needed, study investigators may contact oncologists by phone to obtain or clarify survey information. See Appendix D for the oncologist post-disclosure survey.

C. Parent Surveys. We will conduct a longitudinal study of parents' expectations and perceived utility of their child's genomic test results and of their perceptions of the

disclosure process. We will administer surveys to parents at up to four intervals: (1) at baseline after parents consent to participate in the study, (2) after the return of results, (3) 6 months after return of results and (4) 12 months after return of results. This survey schedule will include parents of children who relapse as well as parents of children who do not relapse. We will not continue to survey parents whose child has died during the course of the study. Parents will receive $25 compensation (either in the form of cash, gift card or debit card depending on the policy of the KidsCanSeq institution) for completing the consent documentation and baseline survey and $10 (again, in the form of either cash, gift card or debit card) each subsequent survey completed. This compensation will be per family i.e., total compensation up to $55 per family. All surveys will be administered either electronically or on paper, in person or remotely. Surveys will be available in English and Spanish. We will aim for the first two surveys to be administered while the parents are still in the clinic (at the time of consent for the baseline survey and after the disclosure session for the post-disclosure survey).

In addition to surveying parents, we will also administer these surveys directly to patients who turn 18 during the course of the study that provide consent to continue participation at the time of re-consent. We will also administer a 6 month follow-up survey to adolescent and young adult (AYA) patients who are at least 15 years old and whose parents have provided permission for direct contact. In the consent form, we ask for parental permission to contact their AYA child directly. For families consented prior to this change, we will contact the AYA's parent via phone (see Phone Script attached in Section S) to obtain their permission to contact minor AYA patients by telephone, email, or text. We will contact eligible AYA patients and invite them to participate in this survey study. We will offer AYA participants $25 compensation (either in the form of cash, gift card or debit card depending on the policy of the KidsCanSeq institution) for their participation. Surveys will be available in English and Spanish.

Baseline Survey. We will administer a baseline survey to parents of all pediatric participants shortly after they give consent to participate in order to assess demographics of participating families, health literacy, attitudes toward genomic sequencing and expectations about its utility. We will invite both parents of each patient to complete baseline surveys. At least one parent must complete the baseline survey within seven days of enrollment for the family to continue study participation (including obtaining tumor and blood samples for testing). This requirement will be covered in detail during the consent session. Families that do not have at least one parent complete the baseline survey will be withdrawn from the study. See Appendix E for the parent baseline survey.

Decliner Survey. We will ask those who decline to have their children enrolled in the study to complete a brief survey assessing barriers to participation, health literacy, and demographic characteristics. Parents will not be compensated for taking the decliner survey. See Appendix G for the parent decliner survey.

Post-Disclosure Survey. Immediately following the result disclosure session, parents will complete a brief post-disclosure survey assessing their perceptions of and general satisfaction with the encounter as well as their perceptions of the degree to which important communication outcomes were achieved. See Appendix I for parent post-disclosure survey.

6-Month Follow-Up Survey. We will survey parents 6 months after receiving results. The 6-month follow-up survey will capture parents' experiences of the benefits and risks of genomic sequencing, attitudes toward genomic sequencing and their utility perceptions. We will compare those who received positive findings to those who received negative findings, those who received germline and tumor results to those who only received germline results, and influence of race/ethnicity. To be consistent with the other CSER consortium sites, the survey will also assess barriers to adherence to surveillance recommendations for parents who received such recommendations for any first degree relatives. See Appendix K for parent 6 month follow-up survey.

AYA 6-Month Follow-Up Survey. We will survey patients who are ≥15 years old and whose parents have provided permission to contact. The AYA follow-up survey will capture patients' perspectives on utility of genetic testing and preferences for decision-making. We will compare AYA patients' perspectives to parents' perspectives and assess differences by participant demographic or type of genetic result received. See Appendix M for AYA 6 month follow-up survey.

1-Year Follow-Up Survey. We may survey parents of patients approximately 1 year after the counseling letter is provided with the specific recommendations made for their disorder. The 1-year follow-up survey may assess healthcare utilization and barriers to adherence to surveillance recommendations, as well as collect data on issues that arise during the course of the project. We will submit the 1-year follow-up survey as an amendment to the IRB when it has been developed.

In order to address attrition and ensure as many surveys are completed as possible, we will follow-up routinely with parents who have not responded to the follow-up surveys by phone and email as well as approaching them in the clinic at the time of appointments. To increase uptake, we will approach parents at their child's 6-month and 1-year follow up appointments and allow them to take the survey at that time in the clinic electronically via a tablet or computer.

9. Implementation of pilot projects to advance the field of genomic medicine in pediatric oncology.

A. **Health Economics**. We will estimate the healthcare costs required to identify mutations that allow clinical intervention through established targeted agents or enrollment onto personalized medicine clinical trials (defined in Aim 1A). We will test

the working hypothesis that targeted gene panels are more cost-effective than genome-scale sequencing methods. We will estimate a cost per actionable target identified as a means for comparing the value of the sequencing methods. With this understanding, we will be poised for incorporating the most efficient method into future clinical practice.

B. Electronic Health Record (EHR). Positive germline results and specific surveillance recommendations will be documented in the patient's EHR. We will develop and implement two clinical decision support (CDS) modules for genomic indications to the KidsCanSeq study and monitor their ability to improve efficiency and facilitate compliance with these surveillance recommendations without being considered intrusive to patient care at Texas Children's Hospital. We will obtain a signed release of information form from the first degree family members at risk for a germline actionable pathogenic variant, and will assess their follow up of recommended testing and surveillance through their EHR.

C. Whole genome sequencing (WGS). Whole genome sequencing (WGS) has the potential to identify genetic alterations of biological and clinical relevance in cancer and blood samples. However the costs associated with WGS are significant, including sequencing, informatics, and data storage. Given this limitation and the technical and interpretative challenges presented by WGS data, routine clinical use of WGS for detecting potentially targetable genetic alterations (to guide cancer therapy) or cancer susceptibility variants (to guide familial genetic testing and cancer surveillance strategies) has been limited. Lack of experience with WGS on formalin-fixed paraffin embedded (FFPE) tumor samples, which are frequently utilized for the clinical tumor testing, also presents a barrier. In order to gain experience with this testing and begin to develop analytic pipelines and interpretative algorithms for analysis of WGS data, we will perform WGS on matched FFPE tumor, frozen tumor, and blood samples of a cohort of BASIC3 patients (n=50) where parents gave permission for additional research sequencing under H-30755.

D. Circulating tumor DNA analysis (ctDNA). We will explore approaches to diagnosing and profiling genomics of pediatric cancers through evaluation of ctDNA extracted from peripheral blood samples as described in Procedure Section 5 above (Additional research genetic studies).

10. Clinical data collection.

Basic demographic and clinical data for each patient enrolled on study will be extracted from the electronic health record (EHR) and recorded in the study specific database maintained by the Office of Research IT in the Pediatrics Research Resources Office, including: date of diagnosis, primary oncologist assigned to the patient, family history

included in the EHR, extent of tumor resection, pathological diagnosis, initial treatment plan, date of tumor recurrence (if applicable), treatment plan chosen at time of recurrence including enrollment on clinical trials (if applicable), and date of death (if applicable). Each subject will be followed for two years to determine the relationship between KidsCanSeq genomic test results and clinical care decisions.

11. Study Newsletters.

Study newsletters may be sent to enrolled families at various time points during the study to update these families on the progress of the study. For those families with deceased patients, an additional cover letter will accompany this study newsletter.

12. CSER Consortium Quality Improvement (QI) Survey.

We will administer the Organizational Readiness to Change Assessment (ORCA) survey, for the purposes of a QI project developed and led by CSER consortium, which the project is part of. Please see Appendix O for QI project details.

C3. Subject Access to Research Related Health Information

All four clinical reports generated from this study will be entered into the patient's electronic health record. As previously described, for patients with negative germline reports, the site project coordinator (PC) will provide parents a packet that includes (1) copies of the targeted panel and WES reports and (2) a genetic counseling letter explaining the significance of negative results in the patient's native language (English or Spanish). For patients with a positive diagnostic, incidental, or carrier status finding, the parents will receive the results from a GC either in person or via telemedicine. Family address will be confirmed at the time of the return of results, and the results will be mailed to family following disclosure. Parents will receive the tumor results from their child's oncologist per routine clinical practice.

C4. Safety Monitoring and Reporting

Protocol Deviations

Protocol deviation is defined as departure from the procedures set forth in the IRB approved protocol and by federal regulations and institutional policies. Participating KCS sites should report deviations and violations to their institution's IRBs as soon as possible per that site's institutional guidelines. Deviations should also be entered into the KCS database, and approvals or acknowledgments from the participating site IRB for protocol deviation will be submitted to the Baylor College of Medicine (BCM) PIs or designee as received (via KCS study database). As needed, the BCM PI or designee will report these protocol variances to the BCM IRB per local policies, i.e., during annual renewal submission.

UPIRSO REPORTING

An Unanticipated Problem Involving Risk to Subjects or Others (UPIRSO) is defined as incident, experience, or outcome that meets all of the following criteria:

1. Unexpected (in terms of the nature, severity or frequency) given

    (a) The description of the likely harms in the protocol, the consent form or the other materials submitted to the IRB and

    (b) The characteristics of the subject population

2. Related to a subject's participation in the research and

3. Suggests that the research places subjects or others at greater risk of harm - physical, psychological, economic or social harms - than was previously known or recognized.

Study subjects should be advised to report any UPIRSOs they experience during the course of their participation in this study from time of consent through the end of the study.

Participating KCS sites are responsible for promptly reporting all UPIRSOs to their local IRB of record as soon as possible per that site's institutional guideline. Sites are responsible for forwarding the IRB approval/acknowledgements to the BCM PI (via KCS study database).

Participating KCS sites are responsible for completing an UPIRSO report in the KCS study database within 48 hours of becoming aware of the event.

The BCM PI or designee will review the completed UPIRSO report and decide whether the UPIRSO meets reporting criteria to the BCM IRB.

D. Sample Size/Data Analysis

D1. Sample Size

We plan to enroll 900 children on study from a KidsCanSeq institution and estimate that at least 825 germline and 270 tumor analyses will be completed. All study patients will have germline sequencing performed. Patients with high risk or recurrent tumors will also undergo tumor sequencing. The original sample size was aimed to enroll 1200 subjects (estimating that 1100 would complete sequencing) to increase power to detect small differences. However, due to NIH-imposed budget cuts, the current estimated sample size was decreased to 900 enrollments. The power calculations provided below are based on the new sample size, however, we will attempt to be as efficient as possible with grant funds to attempt to reach the original sample size of 1100 to be sequenced.
We will increase our sample size by 110 total participants to account for the CSER Consortium QI Survey, the Organizational Readiness to Change Assessment (ORCA) (see Appendix O).

D2. Data Analysis

Because the CSER consortium is focused on harmonization of measures to facilitate cross-consortium analyses, new measures (e.g., surveys, interviews, questionnaires) or revised measures may be introduced throughout the project. Provided here are the KidsCanSeq aims and analyses. Note that the KidsCanSeq project includes support of Drs. Sue Hilsenbeck and Tao Wang of the Dan L Duncan Cancer Center Biostatistical Shared Resource for statistical analysis. They participated in the design of the project and the analyses provided below.

<u>Specific Aim 1.</u> Compare the clinical utility of a targeted gene panel designed for tumor evaluation versus more extensive germline and tumor genomic sequencing in the care of childhood cancer patients.

<u>Specific Aim 1A:</u> Tumor Analysis. Compare the frequency of actionable tumor findings and effect on treatment decisions of the targeted panel (DNA/RNA) versus whole-exome sequencing (WES), transcriptome sequencing, and copy number array of FFPE tumor samples from the subset of study patients with high-risk tumors (n=270 sequenced).

Study 1. Compare the frequency of actionable tumor findings detected by the targeted gene panel alone (panel) versus WES, transcriptome sequencing, and copy number array (integrated testing) and examine the effect of ethnicity. With paired data from 270 high risk cases, and assuming a relatively high correlation between tests (e.g. phi=0.7) and a true rate of actionable somatic cancer gene mutations detected by panel testing of about 20%, absolute increases in yield of 5% or better by the other genomic testing methods (exome, transcriptome and array) will be detectable with greater than 65% power (alpha=5% two-tailed). We expect about 60% of cases will be Hispanic. With a total of 270 cases and an average detection rate of about 20%, absolute differences in rates of about 14% will be detectable using Fisher's exact test with greater than 77% power (alpha=5% two-tailed). Power and sample sizes here and elsewhere have been estimated using PROC POWER in SAS® (Version 9.4), nQueryAdvisor® (version 7.0), and with simulation in R, as appropriate.

Study 2. Compare the effect on treatment decisions (use of agents targeting an actionable mutation) of the panel as compared to integrated testing. Assuming a treatment rate for panel testing of 10% (i.e. half of the 20% of patients with actionable findings are actually treated), and a relatively high correlation between test methods, we can expect to detect absolute differences of about 4% between panel and integrated testing with more than 68% power (alpha=5%, two tailed). Using Fisher's exact test, we will also compare the frequency of targeted agent use in patients with actionable somatic mutations detected by any method compared to those without an

actionable mutation. Assuming at least 20% of cases with actionable mutations (n=54) and 80% without (n=216), we will have more than 70% power (alpha=5%, two-tailed) to detect absolute differences as small as 20% in targeted agent use.

Study 3. Compare the frequency of actionable tumor findings in paired diagnostic and relapsed tumors by both panel and integrated testing. We anticipate that by the end of the study we will have about 75 cases with full tumor testing results on both primary and relapsed tumor, and if we also include previously collected cases from BASIC3, we should have data on about 125 cases altogether. We will estimate the degree of agreement on actionable mutations between diagnosis and relapse and compare the frequencies of actionable mutation. If at least 20% of primaries have an actionable mutation, using the exact McNemar's test and assuming a relatively high correlation, we will have about 71% power (alpha=5% two tailed) to detect an increase to 28% in the relapse.

Study 4. Determine the frequency of cancer gene mutations detected by panel testing and WES that represent germline rather than somatic events. Both tumor and blood samples from the 270 patients will be tested as described. We will determine the frequency with which any mutation detected by sequencing of the tumor sample is also present in the blood sample, i.e. represents a germline variant. We will also estimate this frequency for the subset of tumor actionable mutations. In the event that tumor and germline are not 100% concordant, paired methods like those above will be used to test for differences in mutation frequency. Comparative analyses of germline variation are further described below.

<u>Specific Aim 1B:</u> Germline Analysis. Compare the frequency of diagnostic and/or actionable germline findings from the targeted panel versus WES from a cohort of children with unselected central nervous system (CNS) and non-CNS solid tumors or lymphomas (n=825 sequenced).

Study 1. Determine the overall frequency of germline P/LP variants on the clinical reports from each platform. With 825 cases in KidsCanSeq and assuming a true rate of germline cancer susceptibility mutations (detected by any method) of ~11%, we will be able to estimate the true incidence of reported variants with a 95% confidence interval of +/- 2.1%. We will also estimate concordance of the frequencies of mutations identified by WES compared to panel. With 825 pairs and assuming a reasonably high correlation between the two tests (i.e. Phi coefficient ≥ 0.75) we will have more than 67% power to detect a 2% or greater difference between the platforms (alpha=5% two-tailed). If WES detects all but a few mutations detected by the panel, power will be greater than 90%.

Study 2. Assess whether P/LP variants in common adult cancer genes are enriched in pediatric cancer. We expect such individual susceptibility genes will be mutated in at most 0.7 to 1% of the non-cancer population. In an unpaired analysis using Fisher's exact test, we have >70% power to detect differences between cancer and non-cancer of about 1.1%. These results will clarify whether adult onset cancer genes convey significant pediatric cancer risk.

Study 3. Assess demographic or clinical features which are predictive of a positive germline diagnostic finding. The larger KidsCanSeq study provides additional power to differentiate tumors types that are predictive of germline findings and those with a low yield, such that analysis for any tumor type with at least 75 patients will have >75% power to differentiate a germline diagnostic yield of 3% or less yield compared with study population as a whole.

Study 4. Define the proportion of diagnostic findings which are pediatric "germline actionable" and assess the equivalence of detection by the two diagnostic platforms. %. Using exact McNemer's test, absolute differences of about 1.5 % (e.g., 12% versus 10% diagnostic yield) between testing platforms will be detectable with >65% power (alpha=5%).

Study 5. Determine if the targeted cancer panel could be easily modified to improve efficacy of actionable findings. Based on the WES results additional statistical analyses will generate hypothetical estimates and 90% confidence intervals that might accrue if a small number of the missing genes were added to the panel.

Study 6. Assess the number of pediatric cancer patients with non-cancer secondary actionable findings detected by WES. More quantitative analyses of secondary clinical utility will be performed when combining data across the CSER2 consortium as is currently underway for the first phase of this consortium.

<u>Specific Aim 2</u>. Explore the impact of diagnostic and/or actionable germline findings on genetic testing decisions and healthcare utilization of first degree relatives across the study populations.

<u>Aim 2A:</u> Familial genetic testing. Assess how often first degree relatives of probands with diagnostic and/or actionable germline findings undergo genetic testing and assess differences between populations (in particular Hispanic and non-Hispanic) with regard to accessibility and willingness to undergo testing.

Study 1. Determine the proportion of diagnostic findings in the proband which are *somatic mosaic, de novo* or *inherited.* As we previously reported, in 16 of 20 families (80%) where parental samples were available the cancer susceptibility pathogenic

variant was inherited. However, the estimated rate of *de novo* P/LP variants reported by other investigators (based on family history information) was much higher than the BASIC3 study. Thus, completing this analysis of parents in the larger KidsCanSeq population should further confirm the germline genetic structure of pediatric cancer. This information should be available from the WES report itself if parents have provided samples at entry or will be extracted from follow-up testing of parents.

Study 2. Determine uptake of genetic testing for first degree relatives and whether that varies by ethnicity. Analysis will consist of frequencies and stratified by race, ethnicity and potentially SES status (if sufficient numbers).

Study 3. Determine whether variants detected in patients by germline WES vs targeted panel are more or less likely to result in positive cascade testing of relatives. The hypothesis we are testing is whether WES or panel testing results in more actionable mutations in family members by cascade testing. If there are at least 72 probands with germline actionable mutations, we will detect this difference with 80% power (alpha=5%, one-tailed in favor of WES).

Aim 2B: Familial testing preferences and access to cancer surveillance. Assess differences between populations (in particular Hispanic and non-Hispanic) with regard to uptake of recommended surveillance, availability of services, and other obstacles to obtaining care for relatives who test positive for the genetic findings. Based on our BASIC3 experience, we anticipate that ~107 patients will have actionable germline mutations that will generate an immediate recommendation for testing of family members (predominantly siblings of the proband). Assuming that 80% of actionable variants are inherited, and that cancer patients have on average 1.5 siblings (TCCC data) with 50% likelihood of carrying the variant, we very conservatively estimate 64 variant positive parents and 64 (54 children, 10 adults) variant positive siblings receiving a surveillance recommendation. Expecting 60% of relatives are Hispanic, using Fisher's exact test at a 0.05 significance, we have 60% power to detect an absolute difference in rates of about 27-29% in adults (e.g. 80% in non-Hispanic vs 53% in Hispanic); and about 33-34% in children (e.g. 80% in non-Hispanic vs 47% in Hispanic).

Specific Aim 3. Evaluate the perceived utility of genome sequencing in the care of childhood cancer patients from the perspective of a diverse group of parents and clinicians.

Aim 3A: Parental perceived utility. Determine parents' expectations and experiences of the utility of genomic sequencing across the diverse patient populations of Texas. We will use descriptive statistics to characterize socio-demographic variables, literacy, understanding, and perceived utility of WES. We will use nonparametric methods for

group comparisons to explore whether perceived utility differs by parents' race/ethnicity, gender, education level, or insurance status, as well as between enrolled parents and study decliners, and to assess differences between those who receive positive vs. negative findings, and those who received germline plus tumor sequencing vs. germline sequencing. Generalized linear regression analyses and subgroup analyses by disease risk will also be used to explore the difference in parents' characteristics, and germline and tumor WES results. Using an approximate two-sample t-test and at a 0.05 significance level, we will have 82% power to detect a minimal difference of 0.2 standardized effect size in the perceived utility between ethnic groups. With 107 patients in each group, we will have 82.9% power to detect a difference of 0.4 standardized effect size between the two groups at a 0.05 significance level.

AYA perceived utility. Determine AYA patients' perspectives of the utility of genomic sequencing across diverse healthcare settings in Texas. **Data Analysis:** We will conduct quantitative analysis of survey data to generate descriptive statistics to assess AYA patients' perceived utility of GS, and decision-making role and preferences. Where we have comparable questions in the parent surveys, we will compare responses at the level of the patient-parent pair across groups. We will identify patient attributes associated with particular responses to signal areas for further research on delivery of precision medicine in this population. We will also explore decision-making roles and preferences and perceptions of utility of GS across demographic characteristics in our diverse population. Currently 25% of our study participants are at least 15 years old. Therefore, we expect to have at least 250 potentially eligible AYA participants to approach. Estimating a 30-40% response rate, we expect to survey approximately 75 – 100 AYA participants. As at least 60% of the KCS study population is Hispanic/Latino, we will have diverse ethnic groups to make these assessments. However, due to our limited sample size, we will not have the statistical power to make to make valid cross-group comparisons.

Aim 3B: Oncologist perceived utility. Determine oncologists' expectations and experiences of the utility of genomic sequencing across diverse healthcare settings in Texas. **Data Analysis:** Descriptive statistics will be used to characterize oncologists in terms of socio-demographic variables and perceived utility of WES. For perceived utility measures assessed at baseline and follow-up, we will use nonparametric methods to assess whether significant changes occurred following receipt and return of WES tumor results to parents. We will compare whether physicians who received positive sequencing results for their patient perceived different utility from physicians who did not. Results of the surveys and post-disclosure checklists will be triangulated to explore oncologists' utility perspectives, including new perspectives on utility depending on physician experiences and types of results returned to families.

Specific Aim 4. Develop, implement and evaluate novel, culturally sensitive methods for consent and communicating of complex genomic information in a clinical genomics trial. We expect the educational videos to shorten the staff time spent in consent compared with BASIC3 and increase standardization of genomic information provided the parents across KidsCanSeq institutions. The coordinator at each site will obtain feedback about the video(s) from the first 25 parents enrolling in KidsCanSeq at that site. The feedback will motivate additional changes to the study informed consent procedures as necessary. Scripts in English and Spanish can be made available to the CSER2 Consortium for utilization of applicable components. We will publish on our experience.

Specific Aim 5. Implement pilot projects (health economics, electronic health record and whole genome sequencing) to advance the field of genomic medicine in pediatric oncology. As exploratory pilots our data analysis will be primarily descriptive statistics and serve as preliminary data for future projects or combined with larger cross consortium projects**.**

E. Potential Risks/Discomforts

The physical risks of the study for both patients and parents are minimal and are related to obtaining the blood sample(s). The risks of venipuncture include pain, bleeding, bruising at the venipuncture site, and infection. There is no additional risk to the patient for collection of the tumor sample, since these specimens will only be obtained during the routine clinical care of the patient.

In order to run these genetic tests, it is possible that all of the available patient tumor samples will be used, and therefore no longer be available for future clinical testing or clinical trial enrollment. Each participating KidsCanSeq site will develop a procedure to ensure that tumor samples are only submitted for the study after approval by the clinical team caring for that patient and the lead study oncologist at that site.

There is a potential risk in this type of genetic analysis for uncovering and conveying unexpected information regarding parentage. In addition, the report will include information about the risk of diseases unrelated to cancer if consistent with the patient's phenotype or if the parents have requested medically actionable secondary findings. Disclosure of the inherited exome sequencing results may cause parental anxiety due to the identification of either cancer or non-cancer related medically-actionable inherited variants. These results may have clinical implications for other family members if they have inherited the same mutations.

Generating genomic information on a large scale such as in this study requires special attention to protect patients' rights and confidentiality, since a person's genomic sequence is unique and identifiable. Consequently, there is a risk that others might be able to trace this information back to the patient or other family members, which may impact their ability to obtain life insurance, long-term care insurance or other products that may take into account the results of the sequencing. The inclusion of exome sequencing results into the medical record

(as will occur in this study) increases the risk of this loss of confidentiality. This risk will be explicitly discussed with parents at the time of consent. In addition, with data sharing (genetic, clinical, and other study data such as survey responses) within the CSER study consortium and coded release of parents' genetic information and/or their child's genetic information into scientific databases for other scientists to use, there is also a potentially-increased risk of loss of confidentiality. Genome sequencing and its potential personal risks including loss of confidentiality will be explained to potential participants in the informed consent process. The risk of loss of confidentiality will be protected within the limits allowed by law. Per the new NIH policy this study will have a Certificate of Confidentiality (policy can be viewed at the following link: https://grants.nih.gov/grants/guide/notice-files/NOT-OD-17-109.html).

Since the clinical genomic tests being performed in the study are also provided as part of clinical care for patients outside the study, the risks related to sequencing in this study are not different from standard medical risks of genome-scale testing. However, at this time most subjects in this study would probably not have sequencing as part of their cancer care if they were not enrolled.

F. Potential Benefits

Describe potential benefits to be gained by the individual subject as a result of participating in the planned work.

There may be benefits to subjects or family members if actionable mutations are discovered that would not otherwise have been found or if mutations that impact cancer risk in the patient or family members are discovered. Such actionable mutations could provide additional information regarding diagnosis, prognosis, or possible therapeutic options for the patient/family, including guiding enrollment on clinical trials of molecularly-targeted therapies. It is also possible that participants will receive information about their family's risk of developing cancer that they find reassuring as it was less than anticipated.

Describe potential benefits to society of the planned work.

Genomic technologies are rapidly being incorporated into the clinical care of both children and adults. Development of the technical capabilities and knowledge necessary to utilize these technologies in pediatric oncology in a reliable, ethical, and cost-effective manner has the potential to improve care for children with cancer and provide a model for the responsible incorporation of genomic technology into clinical care. In addition, the identification of the genetic alterations causing cancer development and progression would provide useful biological information about these cancers and potentially lead to improvements in the diagnosis, classification, and treatment of these diseases.

Do anticipated benefits outweigh potential risks? Discuss the risk-to-benefit ratio.

The potential benefit to society of conducting such research in order to study the clinical application of genomic technologies and allow the possibility of improved diagnostics and therapeutics for patients with cancer outweighs the potential risks as listed above.

G. Consent Procedures

1. Enrollment of patients and parents.

Study enrollment at each site will be the responsibility of the designated site project coordinator (PC), who will be supervised by the site study principal investigator (PI; an oncologist). PCs will participate in a webinar training session led by the TCH PC and the TCH genetic counselor (GC). During the training webinar, the project coordinators will learn to obtain informed consent and will be educated about the specific ethical issues related to the acquisition of genomic data.

Once an eligible subject has been identified, the subject's primary oncologist (enrolled in the study) will be contacted for approval to approach the family. After oncologist approval, the site PC or designee will arrange a consent discussion conference with the family, either in person in conjunction (whenever possible) with scheduled clinical visits or via teleconference, i.e., by phone or Zoom (secure, encrypted, HIPAA compliant teleconferencing platform with which BCM has extensive experience).A study education video can be provided (on iPad or by web link) that has been designed to include information about study participation as well as a clinical component explaining genetic testing and the types of results participants may expect to receive. The project coordinator or designee will assess participant understanding of the key study components and answer all questions. The project coordinator or designee will inform parents that at least one parent must also agree to enroll on the study (using the separate study informed consent document for parents). If family agrees to participate, consent documents will be signed and at least one parent must complete the baseline survey within seven days. If the survey is not completed within seven days, sample collection and genetic testing will not proceed and the subject will be removed from the study. Given the potentially time-sensitive need for clinical tumor testing results for high-risk cancer patients, tumor testing may be initiated within the 7 day deadline for baseline survey completion. In such cases the targeted tumor panel testing at a minimum will be completed even if the survey is not completed (and the patient is therefore then removed from the study). Where deemed appropriate by the clinician and the child's parents or guardian, the child will be included in the discussions about the study and verbal or written assent will be obtained per the policy of the KidsCanSeq institution.

Specifically for conferences that occur via teleconference, parents will be initially contacted by phone by the PI or designee for a brief introduction and study description. If the family expresses an interest for further discussion, the family will be sent an electronic invitation via email to connect to a scheduled teleconference. Parents will be able to connect via desktop,

laptop, or mobile device or simply by phone. (Please see separate Parent Phone Consent Script.). Prior to the scheduled teleconference, two copies of the patient and parent consent forms will be forwarded to the family via postal mail (with a self-addressed return envelope) or secure email. After the scheduled teleconference, if the family consents to participate, the family will keep one copy of the patient and parent consent forms and forward signed copies back to the PI or designee. Upon receipt of the signed consent forms, the PI or designee will provide his or her signature. These teleconference consent procedures will be documented. If unavailable (and unable to consent in person at another time following the procedure described above), the first and/or second parent will be consented via phone consent (See separate Parent Phone Consent Script). Enrollment of the second parent on the study will not be required for patient enrollment. As described above, the same procedure will be followed with two copies of the consent form will be forwarded to the second parent. The PI or designee will then consent the second parent over the phone. The second parent will keep one copy of the consent form and forward a signed copy back to the PI or designee. Upon receipt of the signed consent form, the PI or designee will provide his or her signature. This phone consent procedure will be documented.

Together, the Texas KidsCanSeq institutions serve an ethnically and racially diverse patient population. Overall, approximately 15% of parents are estimated speak Spanish as their primary language. For this reason we will also utilize consent forms fully translated into Spanish. We will ensure adequate communication during the consent process by utilizing the translation services available at the KidsCanSeq sites for enrolling Spanish speaking families into treatment trials. Genetic counseling letters sent to families will also be available in English or Spanish per the family's language preference.

In the explanation of the study, the potential risks and benefits of the study (as described in Sections E and F) will be described. Two different consent forms will be used: (1) germline-only consent form for children for whom only germline sequencing will be performed (patients with low risk newly-diagnosed tumors), and (2) combined tumor-germline consent form for children who will undergo both types of testing (patients with high risk newly-diagnosed tumors or refractory/recurrent tumors). The specific risks and benefits of tumor sequencing will only be described in the combined consent form. The germline consent form will explicitly clarify that tumor sequencing will not be performed unless the patient's newly-diagnosed tumor were to become refractory to treatment or return after treatment, in which case the parent would need to be re-consented to allow tumor sequencing utilizing the combined tumor-germline consent form.

The following specific options (not required for study enrollment) will be included in the patient consent form and discussed during the informed consent process:

A. Collection of patient tumor samples for genetic analysis from future or past clinically-indicated cancer surgeries.

B. Whether medically actionable secondary findings (i.e. germline findings not related to patient phenotype) should be disclosed and included in the germline report.
C. Whether the parent gives permission for the study team to contact the patient directly if the patient is 15 years or older to take a survey 6 months after the genetic study results are returned.

Patients who assent to study enrollment as teenagers and then turn eighteen years of age during the two year follow up period will be approached to consent for their continued participation, preferably in person. If these patients are unavailable in person due to the fact they are not returning to clinic frequently, this re-consent process may occur via phone consent. Study coordinator or designee will contact the patient by phone to explain the need for re-consent and to ask permission to send a consent packet (see Age of Majority phone script). If permission is granted, two copies of the consent form will be forwarded to the patient via postal mail, secure email or fax. Once the patient has received the consent packet, the study coordinator or designee will then consent the patient over the phone. The patient will keep one copy of the consent form and forward a signed copy back to the study coordinator or designee via postal mail or fax. Upon receipt of the signed consent form, the study coordinator or designee will provide his or her signature. This phone consent procedure will be documented in the subject's medical record. If the patient cannot be reached by phone, a letter will be mailed to the patient that provides an explanation of the need to re-consent and requests that the patient contact study staff to proceed with the re-consent process via phone. During the re-consent conference whether in person or by phone, patients who have not yet received their genetic test results will be given the opportunity to opt out of sharing their results with their parent(s). For patients who have already received their test results, they will be provided a copy of the original results packet sent to their parents and given the option to review their results with a study genetic counselor.

2. Enrollment of physician subjects.

Each of the pediatric oncologists at the study sites who will potentially care for KidsCanSeq patients will be approached regarding enrollment onto the study. One of the study investigators or a designated study staff member will meet with each physician in person or via teleconference to explain study details, answer questions, offer study enrollment, and obtain informed consent.

H. Confidentiality

Paper files are stored in secured offices and/or in locked file cabinets by the investigators or the clinical research staff. Electronic files are stored in a password protected database. In addition to the clinical laboratories, electronic sequence data will be stored according to

research security standards of Baylor College of Medicine including appropriate cloud-based services.

The clinical genetic reports for each subject will be included in their EHR (in the same manner as for all other clinical tests). For research purposes, apart from the clinical testing and follow-up, subjects will be identified by a separate computer-assigned identifier numbers and codes. The confidentiality of all data will be maintained within legal limits. If subject samples or clinical information is shared with other researchers under an IRB approved protocol, only the research code identifier will be used. These other researchers would not be given access to any identifying information without separate IRB approval. Coded genetic data and clinical information will be released into one or more scientific databases and/or shared with other researchers under IRB-approved protocols. These databases are restricted and can only be accessed by approved researchers. The potential risk of confidentiality associated with release of this coded genetic and clinical data will be explicitly discussed with the subjects, including the small chance that someone could trace the data back to the subject or their close biological relatives.

I. Cost/Payment

Will subject's insurance (or subject) be responsible for research related costs?
There are no costs to the subjects. Their insurance will not be responsible for any research related costs. All costs for the clinical tumor and germline genetic testing at BCM and Texas Children's Hospital will be paid through the research study.

If subjects will be paid (money, gift certificates, coupons, etc.) to participate in this research project, please note the total dollar amount (or dollar value amount) and distribution plan (one payment, pro-rated payment, paid upon completion, etc.) of the payment.

Parents who complete the surveys will receive $25 (in the form of either cash, gift card or debit card depending on the policy of the KidsCanSeq institution) for completion of baseline surveys and $10 (again, in the form of either cash, gift card or debit card) for each subsequent completed survey. Each family could receive up to a total of $55.

AYA study participants will receive $25 (in the form of either cash, gift card or debit card depending on the policy of the KidsCanSeq institution) for the completion of the AYA survey. This compensation can be provided in addition to the $25 - $55 provided to the family after the completion of parent surveys.

J. Genetics

Discuss the potential for psychological, social, and/or physical harm subsequent to participation in this research. Please discuss, considering the following areas: risks to privacy, confidentiality, insurability, employability, immigration status, paternity status, educational opportunities, or social stigma.
There is a potential for psychological harm in genetic testing for uncovering and conveying unexpected information regarding parentage or specific risk of disease. The identity of all subjects will be kept confidential. Generating genomic information on a large scale such as in this study requires special attention to protect patients' rights and confidentiality. The risk of loss of confidentiality is minimal and will be protected within the limits allowed by law. Genome sequencing and its potential personal risks including loss of confidentiality will be explained to potential participants in the informed consent process. The fact that participation in the study includes submission of research data to password protected research databases for general research use (such as the dbGAP database) per the NIH data sharing policy, as well as data sharing within the study consortium, will be included in the consent discussion.

Will subjects be offered any type of genetic education or counseling, and if so, who will provide the education or counseling and under what conditions will it be provided?
Yes, subjects will be offered genetic education and counseling as part of the clinical study. Diagnostic inherited mutation exome data will be disclosed to subjects by the study genetic counselor, so that any medically-actionable mutations identified can be explained and appropriate plans for medical follow-up determined and accomplished. Non-diagnostic inherited mutation exome data will be disclosed to subjects in a genetic counseling letter as previously described. Dr. Plon, a board-certified medical geneticist with expertise in cancer genetics, is available to provide any additional advice to the local physician at the participating KidsCanSeq sites. Dr. Tomlinson is an additional study investigator physician with substantial cancer genetics expertise. The tumor mutation reports will be disclosed to subjects by their treating oncologist so that any tumor mutations that might impact the cancer diagnosis, prognosis, or treatment can be explained and appropriate plans for medical follow-up determined and accomplished. Dr. Parsons, an expert in cancer genomics, and members of the Oncologist Advisory Board will be available to the participating pediatric oncologists to review the testing results and their possible clinical implications.

K. Sample Collection

Patient tumor and blood samples will be collected from KidCanSeq study sites and sent to the TCH MPL for processing, nucleic acid extraction and quantification, and distribution to the clinical sequencing laboratories.

K1. Patient tumor sample

Tumor samples utilized for study purposes will have been collected during medically-indicated procedures, after a sufficient amount of material has been obtained for diagnostic pathological

evaluation. Available samples (formalin-fixed paraffin-embedded, FFPE; or frozen) will be shipped to the TCH Molecular Pathology Laboratories (MPL) for sample processing, extraction of nucleic acids, and distribution of nucleic acids to the clinical sequencing laboratories performing the sequencing tests: the TCH MPL and the Baylor College of Medicine (BCM) Human Genome Sequencing Center-Clinical Laboratory (HGSC-CL) and Baylor Genetics Laboratories (BGL) following standard clinical procedures. Participating study sites will be provided the U01 study as charge source for phlebotomy and sample processing and testing. Subjects will be given the option of allowing tumor samples to be similarly collected from future and previous medically-indicated cancer surgeries.

SAMPLE: Tumor

What is the purpose of the sample collection? The samples will be used for nucleic acid (DNA/RNA) extraction to conduct clinical genetic sequencing in the CAP and CLIA-certified laboratories being utilized for the study. The samples will also be used for DNA, RNA, and protein extraction to conduct additional laboratory research studies including whole genome sequencing methods of detecting genetic alterations.

For blood draws, specify the amount drawn, in teaspoons, at each visit and across the course of the subjects entire participation time. N/A

Is there the possibility that cell lines will be developed with this sample? Yes

Sample will be obtained from: Pathology departments from the following: Texas Children's Hospital/Baylor College of Medicine, Vannie Cook Cancer Clinic, Cook Children's, Children's Hospital of San Antonio, MD Anderson Cancer Center, and UT Health Science Center-San Antonio

Will the sample be stripped of identifiers? No

If sample will be released outside the hospital:
Will sample be released to anyone not listed as an investigator on the protocol? Will the information be identifiable, coded or de-identified? Coded tumor samples or nucleic acids extracted from tumor samples may be shared with other cancer researchers who are conducting IRB-approved research studies.

Will sample material be sold or transferred to any third parties? Will the information be de-identified? No. Samples will not be sold to any third parties.

If sample will be banked for future use: No
Where will the sample be banked and for how long? N/A

Does the banking institution have an approved policy for the distribution of samples? NA

If the entire sample will NOT be used during the course of this research study:
Will the remaining tissue be discarded? If not what will be done with the remaining sample after study completion and how long will the sample be kept? No, the remaining tissue will be kept indefinitely.

Will samples be made available to the research subject (or his/her medical doctor) for other testing? No

If a subject withdraws from the study:
Will subject have the option to get the remaining portion of their sample back? No
Will samples be destroyed? If not, will they be kept anonymously? What will happen to the sample if the subject revokes authorization? If the subject withdraws from the study, his or her sample will be discarded.
Will data obtained from their sample be deleted? What will happen to the sample if the subject revokes authorization? Yes. Data obtained from the sample will be deleted. However, if clinical tumor testing has already been completed and resulting reports have already been entered into the EHR, then these reports will not be deleted. If clinical and genetic data have been included into scientific manuscripts for submission for publication, shared within the study consortium, or released into scientific databases with the subject's consent, it may not be possible to remove this data from the publication or database.

Will study data or test results be recorded in the subject's medical records? Yes. Results of the clinical tumor testing will be recorded in the subject's medical records per standard EHR practices of the participating institutions.

Will results of specific tests and/or results of the overall study be revealed to the research subject and or his/her doctor? Yes

Please identify all third parties, including the subject's physician, to receive the test results. The subject's treating pediatric oncologist will receive test results.

K2. Patient blood sample

SAMPLE: Blood

What is the purpose of the sample collection? The samples will be used for nucleic acid (DNA) extraction to conduct clinical genetic sequencing in the CAP and CLIA-certified laboratories being utilized for the study. The samples will also be used for DNA, RNA,

circulating cells and nucleic acids and protein extraction to conduct additional laboratory research studies including whole genome sequencing methods of detecting genetic alterations.

For blood draws, specify the amount drawn, in teaspoons, at each visit and across the course of the subjects entire participation time. A single blood sample consisting of five teaspoons (25 mLs) of blood will be obtained at initial study enrollment to meet the clinical laboratory requirements for panel and WES tests and additional research genetic studies. The blood sample will not exceed 3 ml per kg of body weight. Additional longitudinal blood samples will also be collected from selected consenting patients (as an opt-in study procedure) approximately every 3-6 months, including at times of key clinical events such as surgical procedures, completion of treatment phases (radiation, chemotherapy), and disease progression or relapse. The volume for these additional blood draws will be approximately 20 mL (not to exceed 3 mL per kg of body weight per 24 hours) and will not exceed 200 mL in total over the course of the study. Whenever possible, all blood samples will be obtained at the time of routine clinically-scheduled blood draws.

Is there the possibility that cell lines will be developed with this sample? Yes

Sample will be obtained from: Clinics and hospitals from the following institutions: Texas Children's Hospital/Baylor College of Medicine, Vannie Cook Cancer Clinic, Cook Children's, Children's Hospital of San Antonio, MD Anderson Cancer Center, and UT Health Science Center-San Antonio.

Will the sample be stripped of identifiers? No

If sample will be released outside the hospital:
Will sample be released to anyone not listed as an investigator on the protocol? Will the information be identifiable, coded or de-identified? Coded blood samples or nucleic acids extracted from blood samples may be shared with other cancer or genetic researchers who are conducting IRB-approved research studies.

Will sample material be sold or transferred to any third parties? Will the information be de-identified? No. Samples will not be sold to any third parties.

If sample will be banked for future use: No
Where will the sample be banked and for how long? N/A
Does the banking institution have an approved policy for the distribution of samples? N/A

If the entire sample will NOT be used during the course of this research study:

Will the remaining tissue be discarded? If not what will be done with the remaining sample after study completion and how long will the sample be kept? No, the remaining blood sample will be kept indefinitely.

Will samples be made available to the research subject (or his/her medical doctor) for other testing? No

If a subject withdraws from the study:
Will subject have the option to get the remaining portion of their sample back? No
Will samples be destroyed? If not, will they be kept anonymously? What will happen to the sample if the subject revokes authorization? If the subject withdraws from the study, his or her sample will be discarded.
Will data obtained from their sample be deleted? What will happen to the sample if the subject revokes authorization? Yes. Data obtained from the sample will be deleted. However, if clinical tumor testing has already been completed and resulting reports have already been entered into the EHR, then these reports will not be deleted. If clinical and genetic data have been included into scientific manuscripts for submission for publication, shared within the study consortium, or released into scientific databases with the subject's consent, it may not be possible to remove this data from the publication or database.
Will study data or test results be recorded in the subject's medical records? Yes. Results of the clinical blood testing will be recorded in the subject's medical records per standard EHR practices of the participating institutions.

Will results of specific tests and/or results of the overall study be revealed to the research subject and or his/her doctor? Yes, the results will be revealed to both the subject and his or her treating oncologist.

Please identify all third parties, including the subject's physician, to receive the test results. In addition to the study genetic counselors, the subject's treating pediatric oncologist will receive test results.

K3. *Patient saliva sample*

If it is not possible to obtain a patient blood sample (preferred sample), a patient saliva sample may be obtained.

SAMPLE: Saliva

What is the purpose of the sample collection? The samples will be used for nucleic acid (DNA) extraction to conduct clinical genetic sequencing in the CAP and CLIA-certified laboratories being utilized for the study. The samples will also be used for DNA, RNA,

circulating cells and nucleic acids and protein extraction to conduct additional laboratory research studies including whole genome sequencing methods of detecting genetic alterations.

For blood draws, specify the amount drawn, in teaspoons, at each visit and across the course of the subjects entire participation time. N/A

Is there the possibility that cell lines will be developed with this sample? Yes

Sample will be obtained from: Saliva collection will be performed at the study sites or by providing parents with saliva collection kits that can be used at home and returned by mail.

Will the sample be stripped of identifiers? No

If sample will be released outside the hospital:
Will sample be released to anyone not listed as an investigator on the protocol? Will the information be identifiable, coded or de-identified? Coded saliva samples or nucleic acids extracted from the saliva samples may be shared with other researchers who are conducting IRB-approved research studies.

Will sample material be sold or transferred to any third parties? Will the information be de-identified? No. Samples will not be sold to any third parties.

If sample will be banked for future use: No
Where will the sample be banked and for how long? N/A
Does the banking institution have an approved policy for the distribution of samples? N/A

If the entire sample will NOT be used during the course of this research study:
Will the remaining tissue be discarded? If not what will be done with the remaining sample after study completion and how long will the sample be kept? No, the remaining saliva sample will be kept indefinitely.

Will samples be made available to the research subject (or his/her medical doctor) for other testing? No

If a subject withdraws from the study:
Will subject have the option to get the remaining portion of their sample back? No
Will samples be destroyed? If not, will they be kept anonymously? What will happen to the sample if the subject revokes authorization? If the subject withdraws from the study, his or her sample will be discarded.

Will data obtained from their sample be deleted? What will happen to the sample if the subject revokes authorization? Yes. Data obtained from the sample will be deleted. However, if clinical saliva testing has already been completed and resulting reports have already been entered into the EHR, then these reports will not be deleted. If clinical and genetic data have been included into scientific manuscripts for submission for publication, shared within the study consortium, or released into scientific databases with the subject's consent, it may not be possible to remove this data from the publication or database.

Will study data or test results be recorded in the subject's medical records? Yes. Results of the clinical saliva testing will be recorded in the subject's medical records per standard EHR practices of the participating institutions.

Will results of specific tests and/or results of the overall study be revealed to the research subject and or his/her doctor? Yes, the results will be revealed to both the subject and his or her treating oncologist.

Please identify all third parties, including the subject's physician, to receive the test results. In addition to the study genetic counselors, the subject's treating pediatric oncologist will receive test results.

K4. Parent saliva sample

Parental saliva samples are not required for the child's enrollment but are routinely requested by the Baylor Genetics Laboratories for confirming the presence and inheritance pattern of mutations identified in the patient that are included in the blood testing reports. Any parent that consents to participate (both biologic parents if available) will be asked to donate saliva to be sent to the TCH MPL for this purpose. Saliva collection will be performed at the study sites or by providing parents with saliva collection kits that can be used at home and returned by mail. Additional genetic studies, including exome sequencing, may be performed on their samples on a research basis.

SAMPLE: Saliva

What is the purpose of the sample collection? The samples will be used for nucleic acid (DNA) extraction for the purpose of confirming the presence and inheritance pattern of mutations identified in the patient (child) that are included in the patient's blood testing reports. The samples will also be used for DNA, RNA, and protein extraction to conduct additional laboratory research studies including whole genome sequencing methods of detecting genetic alterations.

For blood draws, specify the amount drawn, in teaspoons, at each visit and across the course of the subjects entire participation time. N/A

Is there the possibility that cell lines will be developed with this sample? Yes

Sample will be obtained from: Saliva collection will be performed at the study sites or by providing parents with saliva collection kits that can be used at home and returned by mail.

Will the sample be stripped of identifiers? No

If sample will be released outside the hospital:
Will sample be released to anyone not listed as an investigator on the protocol? Will the information be identifiable, coded or de-identified? Coded saliva samples or nucleic acids extracted from the saliva samples may be shared with other researchers who are conducting IRB-approved research studies.

Will sample material be sold or transferred to any third parties? Will the information be de-identified? No. Samples will not be sold to any third parties.

If sample will be banked for future use: No
Where will the sample be banked and for how long? N/A

Does the banking institution have an approved policy for the distribution of samples? N/A

If the entire sample will NOT be used during the course of this research study:
Will the remaining tissue be discarded? If not what will be done with the remaining sample after study completion and how long will the sample be kept? No, the remaining saliva sample will be kept indefinitely.

Will samples be made available to the research subject (or his/her medical doctor) for other testing? No

If a subject withdraws from the study:
Will subject have the option to get the remaining portion of their sample back? No
Will samples be destroyed? If not, will they be kept anonymously? What will happen to the sample if the subject revokes authorization? If the subject withdraws from the study, their sample will be discarded.
Will data obtained from their sample be deleted? What will happen to the sample if the subject revokes authorization? Yes. Data obtained from the sample will be deleted. However, if clinical saliva testing has already been completed and resulting reports have already been entered into the child's electronic health record, then these reports will not be

deleted. If clinical and genetic data have been included into scientific manuscripts for submission for publication, shared within the study consortium, or released into scientific databases with the subject's consent, it may not be possible to remove this data from the publication or database.
Will study data or test results be recorded in the subject's medical records? No

Will results of specific tests and/or results of the overall study be revealed to the research subject and or his/her doctor? Yes, the results will be revealed to both the subject and his or her treating oncologist.

Please identify all third parties, including the subject's physician, to receive the test results. The child's treating pediatric oncologist will receive test results. The parents may share those results (with inheritance pattern/parental status) with their primary care physician.

K5. Parent blood sample

If additional parental germline DNA is needed for study purposes, parents may be asked to provide a blood sample (25 mL), which will be collected at the study site.

SAMPLE: Blood

What is the purpose of the sample collection? The samples will be used for nucleic acid (DNA) extraction for the purpose of confirming the presence and inheritance pattern of mutations identified in the patient (child) that are included in the patient's blood testing reports. The samples will also be used for DNA, RNA, and protein extraction to conduct additional laboratory research studies including whole genome sequencing methods of detecting genetic alterations.

For blood draws, specify the amount drawn, in teaspoons, at each visit and across the course of the subjects entire participation time. A single blood sample consisting of five teaspoons (25 mLs) of blood will be obtained.

Is there the possibility that cell lines will be developed with this sample? Yes

Sample will be obtained from: Blood collection will be performed in clinics or hospitals at the study sites.

Will the sample be stripped of identifiers? No

If sample will be released outside the hospital:
Will sample be released to anyone not listed as an investigator on the protocol? Will the information be identifiable, coded or de-identified? Coded blood samples or nucleic acids

extracted from the blood samples may be shared with other researchers who are conducting IRB-approved research studies.

Will sample material be sold or transferred to any third parties? Will the information be de-identified? No. Samples will not be sold to any third parties.

If sample will be banked for future use: No
Where will the sample be banked and for how long? N/A

Does the banking institution have an approved policy for the distribution of samples? N/A

If the entire sample will NOT be used during the course of this research study:
Will the remaining tissue be discarded? If not what will be done with the remaining sample after study completion and how long will the sample be kept? No, the remaining blood sample will be kept indefinitely.

Will samples be made available to the research subject (or his/her medical doctor) for other testing? No

If a subject withdraws from the study:
Will subject have the option to get the remaining portion of their sample back? No
Will samples be destroyed? If not, will they be kept anonymously? What will happen to the sample if the subject revokes authorization? If the subject withdraws from the study, their sample will be discarded.
Will data obtained from their sample be deleted? What will happen to the sample if the subject revokes authorization? Yes. Data obtained from the sample will be deleted. However, if clinical blood testing has already been completed and resulting reports have already been entered into the child's electronic health record, then these reports will not be deleted. If clinical and genetic data have been included into scientific manuscripts for submission for publication, shared within the study consortium, or released into scientific databases with the subject's consent, it may not be possible to remove this data from the publication or database.
Will study data or test results be recorded in the subject's medical records? No

Will results of specific tests and/or results of the overall study be revealed to the research subject and or his/her doctor? Yes, the results will be revealed to both the subject and his or her treating oncologist.

Please identify all third parties, including the subject's physician, to receive the test results. The child's treating pediatric oncologist will receive test results. The parents may share those results (with inheritance pattern/parental status) with their primary care physician.

Appendix A: KIDSCANSEQ PATIENTS ELIGIBLE FOR TUMOR SEQUENCING

Note: Assignment for each patient will be determined by the KidsCanSeq study team in consultation with the patient's primary oncologist, and subject to review by the Oncologist Advisory Board.

1. Patients with treatment-refractory or recurrent CNS and non-CNS solid tumors, lymphomas, or histiocytic disorders

2. Newly-diagnosed cancer patients with:

A. Diagnostically-challenging tumors

B. Rare tumors without well-defined treatment options

C. High-risk CNS solid tumors including:

- Grade II to IV glial or glioneuronal tumors (e.g. glioblastoma)
- Atypical teratoid/rhabdoid tumor
- Choroid plexus carcinoma
- Malignant meningioma
- Non-germinomatous germ cell tumor
- Pineoblastoma
- PNET/high-grade neuroepithelial tumor
- High-risk medulloblastomas (examples: metastatic; MYC-amplified; anaplastic; or SHH subtype with *TP53* mutation)

D. High-risk non-CNS solid tumors including:

- Metastatic sarcomas or carcinomas of any histology
- Other sarcomas considered high-risk
- Hepatocellular carcinoma
- Renal cell carcinoma
- Rhabdoid tumor
- Colorectal carcinoma
- High-risk neuroblastoma
- Anaplastic Wilms tumor

E. High-risk lymphomas and histiocytic disorders including:

- Histiocytic sarcoma
- Malignant histiocytosis
- Systemic juvenile xanthogranuloma
- Extranodal Rosai-Dorfman disease
- Cutaneous lymphoma (any histology)
- CNS lymphoma (any histology)
- Mature T cell lymphomas
- NK/T cell lymphoma
- Lymphomatoid granulomatosis
- Diffuse large B-cell lymphoma in setting of PTLD

Appendix B: Baseline Oncologist Survey

Thank you for participating in the **KidsCanSeq Study** and for taking time to complete this survey. The purpose of this survey is to understand oncologists' opinions and expectations of the utility of genomic sequencing.

In the KidsCanSeq Study, we will utilize 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. For **tumor** testing we will compare: (1) a targeted gene panel and (2) integrated genomic profiling (whole exome sequencing, RNA sequencing, copy number array). For **germline** testing we will compare (1) a targeted gene 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 will receive all of these types of genetic testing.

In this survey, we will ask you some questions about your attitudes toward genetic testing and some basic questions about yourself.

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 you some questions about what you think about genetic testing.

1. **On a scale of 1 to 5, how beneficial do you think each of the following types of testing is for pediatric cancer patients?**

	Not at all Beneficial (1)	**2**	**3**	**4**	**Extremely Beneficial (5)**
Tumor genetic testing [PRG: If answer 2-5 ask:] Please specify the benefits associated with tumor genetic testing for pediatric cancer patients: [PRG: FREE TEXT]	○	○	○	○	○
Germline genetic testing [PRG: If answer 2-5 ask:] Please specify the benefits associated with germline genetic testing for pediatric cancer patients: [PRG: FREE TEXT]	○	○	○	○	○

2. **On a scale of 1 to 5, how risky do you think each of the following types of testing is for pediatric cancer patients?**

	Not at all Risky (1)	2	3	4	Extremely Risky (5)
Tumor genetic testing [PRG: If answer 2-5 ask:] Please specify the risks associated with tumor genetic testing for pediatric cancer patients: [PRG: FREE TEXT]	○	○	○	○	○
Germline genetic testing [PRG: If answer 2-5 ask:] Please specify the risks associated with germline genetic testing for pediatric cancer patients: [PRG: FREE TEXT]	○	○	○	○	○

3. Please choose the description that best represents your opinion about:

	The benefits outweigh the risks.	The benefits and risks are equal.	The risks outweigh the benefits.
Tumor genetic testing	○	○	○
Germline genetic testing	○	○	○

4. On a scale of 1 to 5, how useful do you think the results from each of the following types of testing will be 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)	○	○	○	○	○

5. Please specify any considerations that influenced your ranking of the relative usefulness of these different types of genetic testing: [PRG: FREE TEXT]

On the scale below, please rate how much you agree or disagree.
I think germline genetic testing will be useful to:

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
6. Help guide decision-making for my patients' cancer care in the event of recurrence	○	○	○	○	○
7. Identify a cause for my patients' cancers	○	○	○	○	○
8. Accurately characterize my patients' risk for disease(s) other than their current cancer diagnosis	○	○	○	○	○
9. Influence what treatment my patients receive for future medical problems not related to cancer	○	○	○	○	○
10. Influence what non-cancer medications my patients take	○	○	○	○	○
11. Influence my patients' future reproductive decisions	○	○	○	○	○
12. Lead my patients' parents to undergo genetic testing or cancer screening	○	○	○	○	○
13. Lead my patients' family members to undergo genetic testing or cancer screening	○	○	○	○	○
14. Provide my patients' parents with information they want	○	○	○	○	○
15. Provide my patients' parents with peace of mind	○	○	○	○	○
16. Relieve my patients' parents from guilt about the possibility that they passed on a gene that contributed to their child getting cancer	○	○	○	○	○
17. 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)	○	○	○	○	○
18. Enable my patients' parents to plan more effectively for the future	○	○	○	○	○

19. Influence my patients' parents' reproductive decisions	○	○	○	○	○

On the scale below, please rate how much you agree or disagree.
I think tumor genetic testing will be useful to:

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

The following questions ask about your general attitudes toward genetics.
Please rate how much you agree or disagree with the following statements.

	Strongly Disagree	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
25. I worry that my patients will have difficulty getting insurance in the future because of their genetic information [PRG: if agree or strongly agree ask:] Which types of insurance are you worried about? Check all that apply: ☐ Health insurance ☐ Life insurance ☐ Disability insurance ☐ Long term care insurance	○	○	○	○	○
26. I worry that my patients will face other kinds of discrimination in the future because of their genetic	○	○	○	○	○

information [PRG: if agree or strongly agree:] Which kinds of discrimination are you worried about? Check all that apply: ☐ Employment-related ☐ Financial ☐ Social ☐ Other, please explain: [PRG: FREE TEXT]					
27. My patients' parents have a right to know their child's genetic information	○	○	○	○	○
28. Parental informed consent should be required for **germline** genetic testing of a child	○	○	○	○	○
29. Parental informed consent should be required for **tumor** genetic testing of a child	○	○	○	○	○
30. Health insurance should cover the cost of **tumor** genetic testing for children with cancer	○	○	○	○	○
31. Health insurance should cover the cost of **germline** genetic testing for children with cancer	○	○	○	○	○
32. Genetic information should be part of a standard medical record	○	○	○	○	○

Lastly, we would like to know about your professional experiences and some basic information about you.

33. How many years have you been in practice (since residency/training ended)?

- ○ 0-5 years
- ○ 6–10 years
- ○ 11–15 years
- ○ 16–20 years
- ○ 21–25 years
- ○ >25 years

34. Have you received any of the following formal genetics education (not including college or professional degree)? Please check all that apply.

- ☐ Genetics residency or fellowship
- ☐ Genetics education course (online or in person)
- ☐ Residency rotation in genetics
- ☐ Graduate degree (in addition to your professional degree) focused on genetics

☐ Other, please specify: [PRG: FREE TEXT]
☐ I have had no formal genetics training

For each item below, please choose the option that best describes your answer.

	Never	Seldom	Sometimes	Often	Almost Always
35. How often do you discuss information about **tumor** genetic testing with your patients and/or their parents?	○	○	○	○	○
36. How often do you discuss information about **germline** genetic testing with your patients and/or their parents?	○	○	○	○	○
37. How often do you order **tumor** genetic testing for your patients?	○	○	○	○	○
38. How often do you order **germline** genetic testing for your patients?	○	○	○	○	○
39. How often do you refer patients to geneticists or genetic counselors?	○	○	○	○	○

40. On a scale of 1 to 5, how important is religion or spirituality in your life?

Not at all Important (1)	2	3	4	Very Important (5)
○	○	○	○	○

41. What year were you born? [PRG: YYYY]

42. What is your gender?

○ Male
○ Female
○ I prefer to self-describe: [PRG: FREE TEXT]
○ I prefer not to answer

43. **Please pick the category that best describes your race/ethnicity. Please check all that apply.**
    - ☐ American Indian or Alaska Native
    - ☐ Asian
    - ☐ Black or African American
    - ☐ Native Hawaiian or Other Pacific Islander
    - ☐ Middle Eastern or North African/Mediterranean
    - ☐ White
    - ☐ Hispanic or Latino
      [if selected]: **Which of these best describes your Hispanic or Latino heritage? Please choose one.** [PRG: DROPDOWN LIST: Argentine, Belizean, Bolivian, Chilean, Colombian, Costa Rican, Cuban, Dominican, Ecuadorian, Guatemalan, Honduran, Mexican, Nicaraguan, Panamanian, Paraguayan, Peruvian, Puerto Rican, Salvadoran, Spaniard, Uruguayan, Venezuelan, More than one heritage (please specify which ones): [FREE TEXT], Other (please specify): [FREE TEXT]]

44. **Do you speak Spanish?**
    - ○ Yes
    - ○ No

45. [PRG: if yes to speak Spanish above, ask:] **Is Spanish your preferred primary language?**
    - ○ Yes
    - ○ No

46. [PRG: if yes to speak Spanish above, ask:] **Which of these best describes the variety/dialect of Spanish that you speak?**
    - ○ Mexican
    - ○ Central American (Belize, Costa Rica, Guatemala, Honduras, Nicaragua, El Salvador)
    - ○ Caribbean (Cuba, Venezuela, Puerto Rico, Dominican Republic, Panama, Caribbean Colombia, Caribbean Mexico)
    - ○ Andean-Pacific (Colombia, Peru, Ecuador, Western Bolivia, Andean Venezuela)
    - ○ Rioplatense (Argentina, Uruguay, Paraguay, Eastern Bolivia)
    - ○ Chilean
    - ○ Iberian (Spain)
    - ○ Other (please specify): [FREE TEXT]

47. [PRG: if yes to speak Spanish above, ask:] **On the scale below, please rate your ability to communicate the following types of information both accurately and fluently in <u>Spanish</u> (proficiency).**

	Elementary proficiency (1)	Limited working proficiency (2)	Professional working proficiency (3)	Full professional proficiency (4)	Bilingual proficiency (5)
General information	○	○	○	○	○
Medical information	○	○	○	○	○
Genetic information	○	○	○	○	○

Thank you for completing this KidsCanSeq Survey!

Appendix C: End of Study Oncologist Survey

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?** (FREE TEXT BOX)

3. **What would you recommend improving about the KidsCanSeq Study? (**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	**Slighty 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? (FREE TEXT BOX**)**

31. What would you recommend improving about the genetic resources available in the KidsCanSeq study? (FREE TEXT BOX**)**

32. **Did you use any resources to help you interpret the <u>sequencing</u> 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: [FREE TEXT BOX]
    - ☐ I did not use any additional resources [PRG: if selected, don't allow selection of other response options]

33. **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: Please describe how you engage your patients who are under 18 years old in these discussions: (Free Text Box)

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

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

35. **Please describe the ways in which your institution is prepared and/or is not prepared to integrate genomic medicine into clinical care:** (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.**

36. 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
37. 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: (Free Text Box)	○	○	○	○
38. Interpreters and I worked well together	○	○	○	○
39. Interpreters helped me notice when families had problems understanding the genetic testing information I presented.	○	○	○	○
40. Interpreters seemed knowledgeable about how to convey the genetic testing information I presented.	○	○	○	○
41. 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!

Appendix D: Oncologist Post-Disclosure Survey

Thank you for your continued participation in the **KidsCanSeq Study** and for taking time to complete this survey.

The purpose of this survey is to understand your opinions regarding the clinical significance of your patient's study results. We will also ask about any clinical actions that you might have taken that were attributable to the tumor and/or germline testing study results.

As a reminder, patients in KidsCanSeq receive both the results of the Mutation Panel (germline) and more extensive genomic testing (germline Whole Exome Sequencing). A link to your patient's germline sequencing reports is provided for your reference.

OR

A link to your patient's tumor and germline sequencing reports is provided. As a reminder, patients in KidsCanSeq receive both the results of the Mutation Panel (tumor DNA and RNA) and Integrated tumor test (exome sequencing, RNA sequencing, copy number array) and Mutation Panel (germline DNA) and more extensive genomic testing (germline Whole Exome Sequencing).

This survey should take about 10-15 minutes to complete.

[PRG: do not show question numbers or letter labels (“a.”) in survey]

[PRG: this survey is sent to physicians only when their patient has received both their tumor (if applicable) AND germline results.]

The survey is about your patient [PRG: patient’s name].

Have you had a medical encounter with your patient since you received their genomic testing results?

- Yes
- No

[PRG: Only show questions T1-T8 for physicians whose patient received a positive tumor finding]

[PRG: Please show at the top of each page for questions T1-T8] **TUMOR SEQUENCING RESULTS**

The following questions are about [PRG: patient’s name]’s positive tumor finding(s), defined as Tier 1 or Tier 2 somatic mutations as per AMP/ASCO/CAP guidelines. Please refer to your patient’s tumor sequencing report(s) here: [PRG: link to this patient’s tumor sequencing reports].

T1. Did these tumor sequencing results provide information relevant to:

1. **The diagnosis of your patient’s tumor?**

   [PRG: If selected]

   Based on study sequencing results, the tumor diagnosis was:

   - Unchanged
   - Changed

   [PRG: If “Changed” selected, show following]

   a. What mutation(s) prompted the change in tumor diagnosis? [PRG: Free text]

   b. What was the new diagnosis after study testing? [PRG: Free text]

□ **The prognosis of your patient’s tumor?**

[PRG: If selected]

a. Based on study sequencing results, the tumor prognosis was:

- Better than previously known
- Worse than previously known

b. What mutation(s) prompted the change in tumor prognosis? [PRG: Free text]

□ **Any treatment decisions or other medical interventions for your patient?**

[PRG: If don’t select 3rd option (“Any treatment decisions…”), skip to T4]

T2. Do you consider any of the tumor alterations identified in your patient to be targetable by a therapeutic agent that is either FDA-approved or in clinical trials (example: a *BRAF* V600E mutation that is targetable with vemurafenib)?

- ○ Yes
- ○ No [PRG: if select No, then skip to T3.]

a. What identified mutation(s) do you consider targetable? [PRG: Free text]

b. Did you recommend treatment with a targeted agent because of the study results?

- ○ Yes
- ○ No [PRG: if select No, then skip to T3.]

c. Was your patient treated with a targeted agent because of the study results?

- ○ Yes
- ○ No [PRG: if select No, then skip to T2f.]

d. What targeted agent did your patient receive? [PRG: Free text]

e. How did your patient receive this targeted agent?

- ○ Enrollment onto a clinical trial
- ○ Use of an FDA-approved targeted agent
- ○ Compassionate use of a non-approved (investigational) agent
- ○ Other (Please specify) [PRG: Free text]

[PRG: if answer T2e, then skip to T3]

f. Why was your patient not treated with a targeted agent? Please select all that apply.

- □ Agent (or formulation) not available
- □ No clinical trial available or patient not eligible for clinical trial
- □ Family preference
- □ Cost of the agent
- □ Progressive disease
- □ Other (Please specify) [PRG: Free text]

T3. Did you recommend any other tumor-directed therapies for your patient because of the study results?

- ○ Yes
- ○ No [PRG: if select No, then skip to T4.]

a. What type of recommendation was made? Please select all that apply.

- □ Start a new medication (please specify) [PRG: Free text]
- □ Stop a current medication (please specify) [PRG: Free text]
- □ Enrollment on a clinical trial (please specify) [PRG: Free text]
- □ Consideration of tumor surgery
- □ Consideration of radiation therapy
- □ Other (Please specify) [PRG: Free text]

b. What mutation(s) prompted these recommendation(s)? [PRG: Free text]

	Not at all Useful (1)	2	3	4	5	6	7	8	9	Extremely Useful (10)
T4. On a scale of 1 to 10, how useful do you think the TUMOR sequencing results are for managing this patient's care now?	○	○	○	○	○	○	○	○	○	○
T5. On a scale of 1 to 10, how useful do you think the TUMOR sequencing results will be for managing this patient's care in the future?	○	○	○	○	○	○	○	○	○	○

	Not at all Likely (1)	2	3	4	5	6	7	8	9	Extremely Likely (10)
T6. On a scale of 1 to 10, how likely are you to order a TUMOR sequencing test in the future for a similar patient if the patient is NOT enrolled on a research study?	○	○	○	○	○	○	○	○	○	○
T7. On a scale of 1 to 10, how likely are you to order a TUMOR sequencing test in the future for a similar patient if the patient is NOT enrolled on a research study and the test is	○	○	○	○	○	○	○	○	○	○

NOT covered by their insurance?										
T8. On a scale of 1 to 10, how likely are you to order a TUMOR sequencing test in the future for a similar patient if the patient is NOT enrolled on a research study and the test IS covered by their insurance?	○	○	○	○	○	○	○	○	○	○

[PRG: Start new Page for Germline results; Show questions G1-G13 for physicians whose patient received a positive germline finding (does not include VUS) OR if selected for negative germline finding.]

[PRG: Please show at the top of each page for questions G1-G13] **GERMLINE SEQUENCING RESULTS**

The following questions are about [PRG: patient's name]'s germline testing, [PRG: if positive results found] which did detect a diagnostic or secondary germline mutation. [PRG: if negative results found] which did NOT detect a diagnostic or secondary germline mutation.

Please refer to your patient's germline sequencing report(s) here: [PRG: link to this patient's germline sequencing reports].

Based on your patient's germline genetic test results, please answer the following questions related to potential genetic diagnoses (including results about your patient's cancer and any other conditions). These questions have been standardized for the purposes of the CSER research consortium and are being asked at each project site for both positive and a sampling of negative germline results.

G1. Based on the information you have now (post study genetic test results), how confident are you that you have identified the primary causal etiology of the patient's condition (cancer)?

- ○ 0, Not at all

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6, Completely

G2. What do you think is the chance that the patient has a genetic condition (either cancer or something else)?

- ○ 0, Definitely not genetic
- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6, Definitely genetic

G3. Were you able to articulate a clear next step to establish a diagnosis based on the germline genetic test results?

- ○ Yes
- ○ No

G4. Were you able to give the patient a clear recommendation for management of symptoms based on germline genetic test results?

- ○ Yes
- ○ No

[PRG: G5 to appear on a NEW PAGE]

The next set of questions are about actions recommended *after receiving the germline results of genetic testing associated with participation in the research study.*

G5. Which of the following did you order or recommend for the participant related to any findings from the germline reports? (*Check all that apply*)

- □ **I didn't order or recommend any of the following** [PRG: If selected make checkboxes below un-selectable]
- □ **A cytogenetic test**
  [PRG: If selected display following]
  (Check all that apply)
  - □ Karyotype only
  - □ Karyotype and microarray
  - □ Microarray only
  - □ Other (Please specify: [PRG: Free Text])
- □ **An additional molecular genetic test**
  [PRG: If selected display following]
  (Check all that apply)
  - □ Single gene test or small panel test (<10 genes)
  - □ Large panel test (<10 genes)
  - □ Large panel test (>10 genes)
  - □ Exome sequencing

- □ Mitochondrial DNA testing
- □ Other (Please specify: [PRG: Free Text])

□ **Other types of laboratory testing**

[PRG: If selected display following]

(Check all that apply)

- □ A metabolic lab test

  [PRG: If selected display following]

  (Check all that apply)
  - □ Plasma amino acids
  - □ Urine organic acids
  - □ Acylcarnitine panel
  - □ Lactate
  - □ Ammonia
  - □ Metabolomic panel
  - □ Transferrin isoelectric focusing
  - □ Guanidinoacetate
  - □ Other (Please specify: [PRG: Free Text])
- □ Endocrine

  [PRG: If selected display following]

  (Check all that apply)
  - □ Thyroid
  - □ Diabetes related
  - □ Adrenal axis
  - □ Other (Please specify: [PRG: Free Text])
- □ Lipids

  [PRG: If selected display following]

  (Check all that apply)
  - □ Cholesterol panel
  - □ Other (Please specify: [PRG: Free Text])
- □ Chromosome stability

  [PRG: If selected display following]

  (Check all that apply)
  - □ DEB breakage
  - □ Telomere length
  - □ Radiation sensitivity
  - □ Other (Please specify: [PRG: Free Text])
- □ Other (Please specify: [PRG: Free Text])

□ **An imaging test**

[PRG: If selected display following]

(Check all that apply)

- □ MRI (Please specify body site(s) and with/without contrast (if known)): [PRG: Free Text])
- □ CT (Please specify body site(s) and with/without contrast (if known)): [PRG: Free Text])
- □ Heart ultrasound/ echocardiography (Please specify: [PRG: Free Text])
- □ Ultrasound of other body parts (Please specify: [PRG: Free Text])
- □ Plain films (Please specify: [PRG: Free Text])

Will anesthesia be required for any of the above?

- ○ Yes

- ○ No

Was the imaging test ordered?

- ○ One time only
- ○ Recurring

□ **A procedure to obtain a tissue sample for additional testing**
[PRG: If selected display following]
(Check all that apply)

- □ Muscle biopsy
- □ Lumbar puncture
- □ Skin biopsy
- □ Other (Please specify: [PRG: Free Text])

Will anesthesia be required for any of the above?

- ○ Yes
- ○ No

□ **Prophylactic Surgery to reduce disease risk**
[PRG: If selected display following]

Please specify: [PRG: Free Text])

□ **Non-invasive electrophysiology**
[PRG: If selected display following]
(Check all that apply)

- □ EKG
- □ EEG
- □ Other (Please specify: [PRG: Free Text])

□ **Invasive electrophysiology**
[PRG: If selected display following]
(Check all that apply)

- □ EMG
- □ Nerve conduction
- □ Other (Please specify: [PRG: Free Text])

□ **Referral to another medical specialty for evaluation or management**
[PRG: If selected display following]
(Check all that apply)

- □ Cardiology
- □ Neurology
- □ Genetics and Metabolism
- □ Ophthalmology
- □ Nephrology
- □ Dermatology
- □ Nephrology
- □ Dermatology
- □ Pulmonology
- □ Immunology/ Allergy
- □ Rheumatology
- □ Hematology
- □ Oncology
- □ Psychiatry

- □ Other (Please specify: [PRG: Free Text])

□ **Referral to a non-MD health professional**
[PRG: If selected display following]
(Check all that apply)
- □ Audiology
- □ Dental
- □ Genetic counselor
- □ Psychologist
- □ Other (Please specify: [PRG: Free Text])

□ **Referral to mental health support**
[PRG: If selected display following]
(Check all that apply)
- □ Mental health
- □ Social support
- □ Palliative care
- □ Other (Please specify: [PRG: Free Text])

□ **Referral for therapeutic services**
[PRG: If selected display following]
(Check all that apply)
- □ Speech therapy
- □ Occupational therapy
- □ Physical therapy
- □ Other (Please specify: [PRG: Free Text])

□ **Other changes to management**
[PRG: If selected display following]
(Check all that apply)
- □ Recommended a new medication (Please specify: [PRG: Free Text])
- □ Recommended a change of dose of an existing medication (Please specify: [PRG: Free Text])
- □ Recommended discontinuation of an existing medication (Please specify: [PRG: Free Text])
- □ Changes to over the counter (OTC) medicines or supplements (Please specify: [PRG: Free Text])
- □ Medical/metabolic diet (Please specify: [PRG: Free Text])
- □ General dietary recommendations (Please specify: [PRG: Free Text])
- □ Recommended change in exercise or level of activity (Please specify: [PRG: Free Text])
- □ Other types of lifestyle changes (Please specify: [PRG: Free Text])
- □ Any other recommendations not covered above (Please specify: [PRG: Free Text])

As part of the study, these results were returned/reviewed with the family by KidsCanSeq study genetic counselors or geneticists, or in the case of negative results were returned via letter. We are also interested in learning whether you also discussed your patient's germline results with their family or took any action based on those results.

G6. Did you discuss the implications of any result for the patient's family members (for example siblings or parents of your patient)?
- ○ Yes
- ○ No [PRG: if select No, then skip to G7.]

a. For which result(s) did you discuss implications for family members? [PRG: Free text]

b. What implications for family members did you discuss? [PRG: Free text]

G7. Did you recommend genetics referral for any of the patient's family members?

- ○ Yes
- ○ No [PRG: if select No, then skip to G8.]

a. For which result(s) did you recommend referral? [PRG: Free text]

b. For which family members did you recommend referral? [PRG: Free text]

G8. Did you recommend genetic testing for any of the patient's family members?

- ○ Yes
- ○ No [PRG: if select No, then skip to G9.]

a. For which result(s) did you recommend testing of family members? [PRG: Free text]

b. Which family members did you recommend get tested? [PRG: Free text]

	Not at all Useful (1)	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**Extremely Useful (10)**
G9. On a scale of 1 to 10, how useful do you think the GERMLINE sequencing results are for managing this patient's care now?	○	○	○	○	○	○	○	○	○	○
G10. On a scale of 1 to 10, how useful do you think the GERMLINE sequencing results will be for managing this patient's care in the future?	○	○	○	○	○	○	○	○	○	○

	Not at all Likely (1)	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**Extremely Likely (10)**

G11. On a scale of 1 to 10, how likely are you to order a GERMLINE sequencing test in the future for a similar patient if the patient is NOT enrolled on a research study?	○	○	○	○	○	○	○	○	○	○
G12. On a scale of 1 to 10, how likely are you to order a GERMLINE sequencing test in the future for a similar patient if the patient is NOT enrolled on a research study and the test is NOT covered by their insurance?	○	○	○	○	○	○	○	○	○	○
G13. On a scale of 1 to 10, how likely are you to order a GERMLINE sequencing test in the future for a similar patient if the patient is NOT enrolled on a research study and the test IS covered by their insurance?	○	○	○	○	○	○	○	○	○	○

Thank you for completing this KidsCanSeq Survey!

Appendix E: Parent Baseline Survey (English)

Thank you for participating in the **KidsCanSeq Study** and for taking time to complete this survey. The purpose of this survey is to understand what parents of children with cancer think about genetic testing. We also want to know what you think about the information you got during the study consent meeting.

You can skip any questions that you do not want to answer. You can stop at any time and restart, or you can do this survey on your own computer. However if you do not finish this survey within the next few days, your child will not be able to receive genetic testing as part of the KidsCanSeq Study. Your answers to these questions have no effect on your child's clinical care.

In this survey, we will also ask you how you feel about learning your child's genetic information. When answering these questions, please do not think about genetic testing your child may have had before enrolling in the KidsCanSeq study (unless we ask you to). We will also ask some basic questions about you, including your and your family's health history.

This survey should take about **30 minutes** to complete.

If you have questions about this study, you can call Robin Raesz-Martinez at (832) 824-7822. If you want to talk to someone who is not a part of this study or if you have concerns or complaints, you can call the Baylor College of Medicine IRB at (713) 798-6970.

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

We would like to know what you think about genetic testing. We're interested in your opinions and there are no right or wrong answers.

I think genetic testing will be useful to:

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. Help with making decisions for cancer that has come back.	○	○	○	○	○
2. Identify a cause for my child's cancer.	○	○	○	○	○
3. Correctly identify my child's chance of developing disease(s) other than the cancer that s/he has now.	○	○	○	○	○
4. Change what treatment my child receives for medical problems in the future that are not related to cancer.	○	○	○	○	○
5. Change what non-cancer medications my child takes.	○	○	○	○	○
6. Influence my child's future decisions to have children or not.	○	○	○	○	○
7. Lead me to get genetic testing or cancer screening.	○	○	○	○	○
8. Lead my family members to get genetic testing or cancer screening.	○	○	○	○	○
9. Give me information that I want.	○	○	○	○	○
10. Give me peace of mind.	○	○	○	○	○
11. Let me plan better for the future.	○	○	○	○	○
12. Influence my reproductive decisions.	○	○	○	○	○

Please tell us what you think about these statements.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
13. I feel comfortable letting researchers use my child's genetic information as long as they don't use his/her name.	○	○	○	○	○

14. My child's oncologist knows enough to help me understand my child's genetic information.	○	○	○	○	○
15. I trust doctors who do medical research.	○	○	○	○	○
16. I'm worried about being able to cope with my child's genetic information.	○	○	○	○	○
17. I'm worried that I passed genes onto my child that played a role in him/her getting cancer.	○	○	○	○	○
18. [PRG: if agree or strongly agree in Q17:] I think genetic testing will be useful to help lessen any guilt I might feel that I passed genes onto my child that played a role in him/her getting cancer.	○	○	○	○	○
19. I'm worried that something that I did or did not do played a role in my child getting cancer (other than passing on a gene).	○	○	○	○	○
20. [PRG: if agree or strongly agree in Q19:] I think genetic testing will be useful to help lessen any guilt I might feel that I did or did not do something that played a role in my child getting cancer (other than passing on a gene).	○	○	○	○	○
21. I'm worried about the privacy of my child's genetic information.	○	○	○	○	○
22. I'm worried that my child will not be able to get insurance because of his/her genetic information. [PRG: if agree or strongly agree ask:] Which kinds of insurance are you worried about? Check all that apply: ☐ Health insurance ☐ Life insurance ☐ Disability insurance	○	○	○	○	○

☐ Long term care insurance					
23. I'm worried that my child will be treated in unfair ways because of his/her genetic information. [PRG: if agree or strongly agree:] Which kinds of unfair treatment are you worried about? Check all that apply: ☐ Job-related ☐ Financial (for example, not being able to get a loan from a bank) ☐ Social ☐ Other, please explain: [PRG: FREE TEXT]	○	○	○	○	○
24. Health insurance should pay for genetic testing for children with cancer.	○	○	○	○	○

25. On a scale of 1 to 5, how beneficial do you think genetic testing is for children with cancer?

Not at all Beneficial (1)	2	3	4	Extremely Beneficial (5)
○	○	○	○	○

[PRG: If answer 2 through 5 ask:] **Please tell us what you think the benefits of genetic testing are for children with cancer:** [PRG: FREE TEXT]

26. On a scale of 1 to 5, how risky do you think genetic testing is for children with cancer?

Not at all Risky (1)	2	3	4	Extremely Risky (5)
○	○	○	○	○

[PRG: If answer 2 through 5 ask:] **Please tell us what you think the risks of genetic testing are for children with cancer:** [PRG: FREE TEXT]

27. Please choose the description that is closest to what you think about genetic testing for children with cancer.

There are more benefits than risks.	There are an equal amount of benefits and risks.	There are more risks than benefits.

○	○	○

The next questions ask about your experience with genetic testing **before** you were in the KidsCanSeq Study.

28. Who in your family has had genetic testing? Please check all that apply.

- ☐ Me
- ☐ My child's other biological parent
- ☐ My child participating in KidsCanSeq
- ☐ My other children
- ☐ No one in my immediate family has had genetic testing

[PRG: For each response selected in above Q, show next 4 Qs. If select "no one in my immediate family has gotten genetic testing" then skip next 4 Qs:]

29. Why did [PRG: based on response above: **you** OR **your child's other biological parent,** OR **your child participating in KidsCanSeq** OR **your other children**] **have genetic testing? Please check all that apply.**

- ☐ For medical reasons (for example, for a particular medical condition that this person has or that runs in the family)
- ☐ Prenatal testing [PRG: don't show if "My child participating in KidsCanSeq" chosen above]
- ☐ To learn about where my family came from (ancestry)
- ☐ To personalize medications using genetic information
- ☐ To see who the father of my child is (paternity)
- ☐ For a different research study
- ☐ Other, please describe: [FREE TEXT]

30. What kind of genetic testing was done? [PRG: FREE TEXT]

31. When was this genetic testing done? [PRG: YYYY]

32. On a scale of 1 to 5, how useful did you find the test result?

Not at all Useful (1)	2	3	4	Extremely Useful (5)
○	○	○	○	○

Please tell us how the test result was useful or not to you: [PRG: FREE TEXT]

The next questions are to help us know more about how people understand information. Knowing what you prefer and need helps us make better materials for future studies.

33. How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read medical materials?

- ○ Always
- ○ Often
- ○ Sometimes
- ○ Occasionally
- ○ Never

34. How often do you have problems learning about your medical conditions because of difficulty understanding written information?

- ○ Always
- ○ Often
- ○ Sometimes
- ○ Occasionally
- ○ Never

35. How often do you have a problem understanding what is told to you about your medical condition?

- ○ Always
- ○ Often
- ○ Sometimes
- ○ Occasionally
- ○ Never

36. How confident are you filling out medical forms by yourself?

- ○ Extremely
- ○ Quite a bit
- ○ Somewhat
- ○ A little bit
- ○ Not at all

Please rate yourself on the scales below.

37. How good are you at working with fractions?

Not at all (1)	**2**	**3**	**4**	**5**	**Extremely good (6)**
○	○	○	○	○	○

38. How good are you at figuring out how much a shirt will cost if it is 25% off?

Not at all (1)	**2**	**3**	**4**	**5**	**Extremely good (6)**

○	○	○	○	○	○

39. How often do you find numerical information to be useful?

Never (1)	2	3	4	5	Very often (6)
○	○	○	○	○	○

There are many reasons why you might not take your child to a doctor. We would like to know if any of these situations have applied to you.

40. Has there been any time in the last 12 months when you wanted or needed your child to see a doctor or health care professional and did not?

- ○ Yes
- ○ No

41. [PRG: if yes to above:] Why did your child not see a doctor or health care professional when you wanted or needed them to in the last year? Please select all that apply.

- ☐ I could not afford it.
- ☐ It was too difficult to get there.
- ☐ I do not like doctors and avoid going.
- ☐ I did not want to get bad news.
- ☐ I did not have time.
- ☐ I decided to take care of it on my own.
- ☐ I decided to wait and see if the problem would go away on its own.
- ☐ The doctor was not available to see my child.
- ☐ The insurance company would not approve, cover, or pay for medical care.
- ☐ The doctor refused to accept insurance plan.
- ☐ I could not get time off work.
- ☐ I did not know where to go to get medical care.
- ☐ I was refused services.
- ☐ I could not get child care.
- ☐ COVID-19 (novel coronavirus) pandemic [PRG: if selected: Please describe: [PRG: FREE TEXT]
- ☐ Other (please describe): [PRG: FREE TEXT]

42. What is your date of birth? [PRG: MM/DD/YYYY]

43. What is the gender of your child participating in KidsCanSeq?

- ○ Male
- ○ Female
- ○ Prefer to self-describe: [PRG: FREE TEXT]

- ○ Prefer not to say

44. What is your gender?

- ○ Male
- ○ Female
- ○ I prefer to self-describe: [PRG: FREE TEXT]
- ○ I prefer not to say

45. What category or categories best describe your child participating in KidsCanSeq? Please check all that apply.

- ☐ American Indian, Native American, or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or Pacific Islander
- ☐ White or European American
- ☐ Middle Eastern or North African/Mediterranean
- ☐ Hispanic or Latino
  [if selected]: **Which of these best describes your child's Hispanic or Latino heritage? Please choose one.** [PRG: DROPDOWN LIST: Argentine, Belizean, Bolivian, Chilean, Colombian, Costa Rican, Cuban, Dominican, Ecuadorian, Guatemalan, Honduran, Mexican, Nicaraguan, Panamanian, Paraguayan, Peruvian, Puerto Rican, Salvadoran, Spaniard, Uruguayan, Venezuelan, More than one heritage (please describe which ones): [FREE TEXT], Other (please describe): [FREE TEXT]]
- ☐ I prefer not to answer
- ☐ Unknown/none of these fully describe my child participating in KidsCanSeq

46. What category or categories best describe you? Please check all that apply.

- ☐ American Indian, Native American, or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or Pacific Islander
- ☐ White or European American
- ☐ Middle Eastern or North African/Mediterranean
- ☐ Hispanic or Latino
  [if selected]: **Which of these best describes your Hispanic or Latino heritage? Please choose one.** [PRG: DROPDOWN LIST: Argentine, Belizean, Bolivian, Chilean, Colombian, Costa Rican, Cuban, Dominican, Ecuadorian, Guatemalan, Honduran, Mexican, Nicaraguan, Panamanian, Paraguayan, Peruvian, Puerto Rican, Salvadoran, Spaniard, Uruguayan, Venezuelan, More than one heritage (please describe which ones): [FREE TEXT], Other (please describe): [FREE TEXT]]
- ☐ I prefer not to answer

☐ Unknown/none of these fully describe me

47. [PRG: Only show in English version of survey:] **Do you speak another language besides English?**

- ○ Yes [PRG: If selected, show next 2 Qs]
- ○ No

48. How well do you speak English?

- ○ Native English speaker
- ○ Very well
- ○ Well
- ○ Not well

49. What language do you prefer to speak with your child's doctors?

- ○ English
- ○ Another language
- ○ I am equally comfortable discussing my child's medical care in both English and another language

50. [PRG: If "another language" selected in above Q:] **Please tell us which language you prefer to speak with your child's doctors:** [PRG: DROPDOWN LIST:] Spanish, Vietnamese, Chinese (Mandarin, Cantonese, or other Chinese language), Tagalog, German, French, Korean, Russian, Arabic, Other (please describe): [PRG: FREE TEXT]

51. Which of these best describes you?

- ○ Married
- ○ Widowed
- ○ Divorced
- ○ Separated
- ○ Never married
- ○ Living with partner

52. On a scale of 1 to 5, how important is <u>religion</u> or <u>spirituality</u> in your life?

Not at all Important (1)	2	3	4	Extremely Important (5)
○	○	○	○	○

53. What is the highest grade level of school you completed or the highest degree you received?

- ○ Less than high school (less than 9th grade)
- ○ Some high school (9th to 12th grade), no diploma

- ○ High school graduate (diploma or GED or equivalent)
- ○ Some college or occupational, technical, or vocational training, no degree or certificate
- ○ Associate (2-year) college degree, or completed occupational, technical, or vocational program and received degree or certificate
- ○ Bachelor's degree (for example: BA, AB, BS)
- ○ Graduate or professional degree (for example: MA, MBA, JD, MD, PhD)

54. What was your household's total family income (before taxes) from all sources in the last year? Please select one.

- ○ Less than $20,000
- ○ $20,000 to $39,999
- ○ $40,000 to $59,999
- ○ $60,000 to $79,999
- ○ $80,000 to $99,999
- ○ $100,000 to $139,999
- ○ $140,000 or more

55. How many people (children and adults) were supported by this income in the last year? [PRG: numerical field, 1-20 valid]

56. Before becoming sick, was your child living in the United States?

- ○ Yes
- ○ No [PRG: if selected don't ask next Q and ask:] Where was your child living? [PRG: FREE TEXT]

57. [PRG: if yes:] **Before becoming sick, what was the zip code of where your child lived?** [PRG: FREE TEXT]

58. Is your child covered by health insurance or some other kind of health care plan? (Include health insurance obtained through employment or purchased directly as well as government programs like Medicare and Medicaid that provide medical care or help pay medical bills).

- ○ Yes
- ○ No

59. [PRG: if yes:] **What kind or kinds of health insurance or health care coverage does your child have? (Check all that apply)**

- ☐ Private health insurance, employment based
- ☐ Private health insurance, directly purchased
- ☐ Government plan, Medicare
- ☐ Government plan, Medicaid
- ☐ Government plan, Military health care such as TRICARE and CHAMPVA
- ☐ Government/State plan, Children's Health Insurance Plan (CHIP)
- ☐ Other type of insurance (please describe): [PRG: FREE TEXT]

60. **Are you covered by health insurance or some other kind of health care plan? (Include health insurance obtained through employment or purchased directly as well as government programs like Medicare and Medicaid that provide medical care or help pay medical bills).**
    - ○ Yes
    - ○ No

61. [PRG: if yes:] **What kind or kinds of health insurance or health care coverage do you have? (Check all that apply)**
    - ☐ Private health insurance, employment based
    - ☐ Private health insurance, directly purchased
    - ☐ Government plan, Medicare
    - ☐ Government plan, Medicaid
    - ☐ Government plan, Military health care such as TRICARE and CHAMPVA
    - ☐ Government/State plan, Children's Health Insurance Plan (CHIP)
    - ☐ Other type of insurance (Please describe): [PRG: FREE TEXT]

In this last section, we would like to know health history information about your child's biological relatives.

62. **Are you your child's biological parent?**
    - ○ Yes, I'm my child's biological mother. [PRG: if selected direct to complete biological mother information but don't ask last/first name, sex, age, or living or deceased, and remove "I don't know" option from History of Cancer]
    - ○ Yes, I'm my child's biological father [PRG: if selected, direct to complete biological father information but don't ask last/first name, sex, age, or living or deceased, and remove "I don't know" option from History of Cancer]
    - ○ No, I'm not my child's biological parent [PRG: if selected, show Q63]

63. [PRG: if either Yes response selected in Q62] **Do you know any health history information about your child's other biological parent?**
    - ○ Yes [PRG: if selected, direct to complete health history information for other biological parent depending on Q62 (if mother taking survey then give Qs about father, and vice versa)]
    - ○ No [PRG: if selected, skip to Q65]

64. **Do you know any health history information about your child's biological parents? Please select all that apply.**
    - ☐ Yes, biological mother [PRG: if selected, direct to complete biological mother information]
    - ☐ Yes, biological father [PRG: if selected, direct to complete biological father information]
    - ○ I don't know any information about my child's biological parents. [PRG: if selected, don't allow selection of other options and don't ask Qs about biological parents]

	Biologic Mother	Biologic Father
Last Name	[PRG: FREE TEXT]	[PRG: FREE TEXT]
First Name	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Sex	[PRG: DROPDOWN LIST, values: Male, Female, Other]	[PRG: DROPDOWN LIST, values: Male, Female, Other]
Age	[PRG: numerical field]	[PRG: numerical field]
Living or Deceased?	[PRG: DROPDOWN LIST, values: Living, Deceased, I don't know]	[PRG: DROPDOWN LIST, values: Living, Deceased, I don't know]
[PRG: If "Deceased":] Age at Death	[PRG: numerical field]	[PRG: numerical field]
[PRG: If "Deceased":] Cause of Death	[PRG: FREE TEXT]	[PRG: FREE TEXT]
History of Cancer?	[PRG: Options: Yes, No, I don't know]	[PRG: Options: Yes, No, I don't know]
[PRG: If "Yes" to History of Cancer:] Type of Cancer Diagnosis	[PRG: FREE TEXT]	[PRG: FREE TEXT]
[PRG: If "Yes" to History of Cancer:] Age at Cancer Diagnosis	[PRG: numerical field]	[PRG: numerical field]

65. Does your child have any full siblings (siblings that share the same biologic mother and father)?

- ○ Yes [PRG: if yes, show:] **How many?** [PRG: numerical field]
- ○ No
- ○ I don't know

66. [PRG: if yes to above, show:] **Please tell us about your child's full siblings.**

[PRG: questions should appear for however many siblings selected in previous Q]

	Full Sibling 1	Full Sibling 2
Last Name	[PRG: FREE TEXT]	[PRG: FREE TEXT]
First Name	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Sex	[PRG: DROPDOWN LIST, values: Male, Female, Other]	[PRG: DROPDOWN LIST, values: Male, Female, Other]
Age	[PRG: numerical field]	[PRG: numerical field]
Is this child adopted?	[PRG: DROPDOWN LIST, values: Yes, No]	[PRG: DROPDOWN LIST, values: Yes, No]

Living or Deceased?	[PRG: Options: Living, Deceased, I don't know]	[PRG: Options: Living, Deceased, I don't know]
[PRG: If "Deceased":] Age at Death	[PRG: numerical field]	[PRG: numerical field]
[PRG: If "Deceased":] Cause of Death	[PRG: FREE TEXT]	[PRG: FREE TEXT]
History of Cancer?	[PRG: Options: Yes, No, I don't know]	[PRG: Options: Yes, No, I don't know]
[PRG: If "Yes" to History of Cancer:] Type of Cancer Diagnosis	[PRG: FREE TEXT]	[PRG: FREE TEXT]
[PRG: If "Yes" to History of Cancer:] Age at Cancer Diagnosis	[PRG: numerical field]	[PRG: numerical field]

67. **Does your child have any half siblings related through** [PRG: if biological mother selected in Q62, then: "**you**" otherwise: "**his/her biologic mother**"]**?**
    - ○ Yes [PRG: if yes, show:] **How many?** [PRG: numerical field]
    - ○ No
    - ○ I don't know

68. [PRG: if yes to above, show:] **Please tell us about your child's half siblings, related through** [PRG: if biological mother selected in Q62 then: **"you**" otherwise: **"his/her biologic mother."**]

[PRG: Qs should appear for however many half siblings selected in previous Q]

	Maternal Half Sibling 1	**Maternal Half Sibling 2**
Last Name	[PRG: FREE TEXT]	[PRG: FREE TEXT]
First Name	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Sex	[PRG: DROPDOWN LIST, values: Male, Female, Other]	[PRG: DROPDOWN LIST, values: Male, Female, Other]
Age	[PRG: numerical field]	[PRG: numerical field]
Is this child adopted?	[PRG: DROPDOWN LIST, values: Yes, No]	[PRG: DROPDOWN LIST, values: Yes, No]
Living or Deceased?	[PRG: Options: Living, Deceased, I don't know]	[PRG: Options: Living, Deceased, I don't know]
[PRG: If "Deceased":] Age at Death	[PRG: numerical field]	[PRG: numerical field]
[PRG: If "Deceased":] Cause of Death	[PRG: FREE TEXT]	[PRG: FREE TEXT]
History of Cancer?	[PRG: Options: Yes, No, I don't know]	[PRG: Options: Yes, No, I don't know]

[PRG: If "Yes" to History of Cancer:] Type of Cancer Diagnosis	[PRG: FREE TEXT]	[PRG: FREE TEXT]
[PRG: If "Yes" to History of Cancer:] Age at Cancer Diagnosis	[PRG: numerical field]	[PRG: numerical field]

69. **Does your child have any half siblings related through** [PRG: if biological father selected in Q62, then: "**you**" otherwise "**his/her biologic father**"]**?**
    - ○ Yes [PRG: if yes, show:] **How many?** [PRG: numerical field]
    - ○ No
    - ○ I don't know

70. [PRG: if yes to above, show:] **Please tell us about your child's half siblings, related through** [PRG: if biological father selected in Q62 then: **"you**" otherwise: **"his/her biologic father."**]

[PRG: Qs should appear for however many half siblings selected in previous Q]

	Paternal Half Sibling 1	**Paternal Half Sibling 2**
Last Name	[PRG: FREE TEXT]	[PRG: FREE TEXT]
First Name	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Sex	[PRG: DROPDOWN LIST, values: Male, Female, Other]	[PRG: DROPDOWN LIST, values: Male, Female, Other]
Age	[PRG: numerical field]	[PRG: numerical field]
Is this child adopted?	[PRG: DROPDOWN LIST, values: Yes, No]	[PRG: DROPDOWN LIST, values: Yes, No]
Living or Deceased?	[PRG: Options: Living, Deceased, I don't know]	[PRG: Options: Living, Deceased, I don't know]
[PRG: If "Deceased":] Age at Death	[PRG: numerical field]	[PRG: numerical field]
[PRG: If "Deceased":] Cause of Death	[PRG: FREE TEXT]	[PRG: FREE TEXT]
History of Cancer?	[PRG: Options: Yes, No, I don't know]	[PRG: Options: Yes, No, I don't know]
[PRG: If "Yes" to History of Cancer:] Type of Cancer Diagnosis	[PRG: FREE TEXT]	[PRG: FREE TEXT]
[PRG: If "Yes" to History of Cancer:] Age at Cancer Diagnosis	[PRG: numerical field]	[PRG: numerical field]

Thank you for participating in the KidsCanSeq Study and completing this survey!

Appendix F: Parent Baseline Survey (Spanish)

Gracias por participar en el **Estudio KidsCanSeq** y por tomarse el tiempo para completar esta encuesta. El propósito de esta encuesta es entender qué es lo que piensan los padres de niños con cáncer sobre las pruebas genéticas. Asimismo, deseamos saber qué piensa sobre la información que recibieron durante la reunión de consentimiento del estudio.

Puede saltarse cualquier pregunta que no desee responder. Puede detenerse en cualquier momento y volver a comenzar, o puede completar esta encuesta en su propia computadora. Sin embargo, si no completa esta encuesta dentro de los siguientes días, su hijo(a) no podrá recibir la prueba genética como parte del Estudio KidsCanSeq. Sus respuestas a estas preguntas no tienen ningún efecto en el cuidado clínico de su hijo(a).

En esta encuesta, también le preguntamos cómo se siente sobre conocer la información genética de su hijo(a). Al responder estas preguntas, por favor no piense en las pruebas genéticas que su hijo(a) pueda haber tenido antes de inscribirse en el estudio KidsCanSeq (a menos que se lo solicitemos). Asimismo, también le haremos algunas preguntas básicas sobre usted, incluyendo su historial de salud y el de su familia.

Esta encuesta le tomará aproximadamente **30 minutos** para completarla.

Si tiene alguna pregunta sobre este estudio, puede comunicarse con Robin Raesz-Martinez al (832)-824-7822. Si desea hablar con alguien que no es parte de este estudio o si tiene preocupaciones o quejas, puede llamar a la IRB de Baylor College of Medicine al (713) 798-6970.

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

Usaremos "tú" en esta encuesta para referirnos a usted, el padre o la madre del paciente.

Nos gustaría saber qué piensas sobre las pruebas genéticas. Estamos interesados en tus opiniones y no hay respuestas correctas o incorrectas.

Pienso que las pruebas genéticas serán útiles para:

	Definitivamente no estoy de acuerdo	**No estoy de acuerdo**	**Neutral**	**Estoy de acuerdo**	**Definitivamente estoy de acuerdo**
1. Ayudar a tomar decisiones relacionadas al cáncer que ha vuelto.	○	○	○	○	○
2. Identificar una causa del cáncer de mi hijo(a).	○	○	○	○	○
3. Identificar si mi hijo(a) puede desarrollar otra(s) enfermedad(es) además del cáncer que él/ella tiene ahora.	○	○	○	○	○
4. Cambiar el tratamiento que mi hijo(a) recibirá en el futuro por si acaso tiene problemas médicos que no estén relacionados con el cáncer.	○	○	○	○	○
5. Cambiar los medicamentos que toma mi hijo(a) que no son para el cáncer.	○	○	○	○	○
6. Influir en la decisión de mi hijo(a) de tener hijos o no en el futuro.	○	○	○	○	○
7. Mandar hacerme pruebas genéticas o pruebas de cáncer.	○	○	○	○	○

8. Llevar a los miembros de mi familia a hacerse pruebas genéticas o de cáncer.	○	○	○	○	○
9. Darme información que yo deseo.	○	○	○	○	○
10. Darme tranquilidad.	○	○	○	○	○
11. Dejarme planear mejor el futuro.	○	○	○	○	○
12. Influir en mis decisiones reproductivas.	○	○	○	○	○

Por favor dinos qué piensas sobre estas declaraciones.

	Definitivamente no estoy de acuerdo	**No estoy de acuerdo**	**Neutral**	**Estoy de acuerdo**	**Definitivamente estoy de acuerdo**
13. Me siento cómodo/a permitiendo que los investigadores utilicen la información genética de mi hijo(a) siempre y cuando no utilicen su nombre.	○	○	○	○	○
14. El oncólogo de mi hijo(a) sabe lo suficiente para ayudarme a comprender la información genética de mi hijo(a).	○	○	○	○	○
15. Confío en los médicos que realizan estudios de investigación clínica.	○	○	○	○	○
16. Estoy preocupado/a sobre mi habilidad para lidiar con la información genética de mi hijo(a).	○	○	○	○	○
17. Estoy preocupado/a de haberle pasado genes a mi hijo(a) que han jugado un papel en el que él/ella se enfermó de cáncer.	○	○	○	○	○

18. [PRG: if “Estoy de acuerdo” or “Definitivamente estoy de acuerdo” in Q17:] Creo que las pruebas genéticas serán útiles para disminuir cualquier culpa que pueda sentir de haberle pasado genes a mi hijo(a) que han jugado un papel en el que él/ella se enfermó de cáncer.	○	○	○	○	○
19. Estoy preocupado/a de que algo que hice o no hice haya jugado un papel en el que mi hijo(a) se enfermó de cáncer (además de pasarle un gen).	○	○	○	○	○
20. [PRG: if “Estoy de acuerdo” or “Definitivamente estoy de acuerdo” in Q19:] Pienso que las pruebas genéticas serán útiles para disminuir cualquier culpa que pueda sentir por haber hecho o no haber hecho algo que haya jugado un papel en el que mi hijo(a) se enfermó de cáncer (además de pasarle un gen).	○	○	○	○	○
21. Estoy preocupado/a por la privacidad de la información genética de mi hijo(a).	○	○	○	○	○
22. Estoy preocupado/a de que mi hijo(a) no pueda obtener un seguro debido a los resultados de las pruebas genéticas. [PRG: if “Estoy de acuerdo” or “Definitivamente estoy	○	○	○	○	○

de acuerdo" ask:] ¿Por qué tipos de seguro estás preocupado/a? Por favor, marca todos los que correspondan: ☐ Seguro de salud ☐ Seguro de vida ☐ Seguro por discapacidad ☐ Seguro de cuidados a largo plazo					
23. Estoy preocupado/a de que mi hijo(a) sea tratado injustamente por su información genética. [PRG: if "Estoy de acuerdo" or "Definitivamente estoy de acuerdo":] ¿Qué tipo de tratamiento injusto te preocupa? Por favor, marca todos los que correspondan: ☐ Relacionado con el trabajo ☐ Financiero (por ejemplo, no poder obtener un préstamo bancario) ☐ Social ☐ Otros, por favor explica: [PRG: FREE TEXT]	○	○	○	○	○
24. El seguro de salud debería pagar las pruebas genéticas para niños con cáncer.	○	○	○	○	○

25. En una escala del 1 al 5, ¿qué tan beneficiosas crees que son las pruebas genéticas para niños con cáncer?

Nada beneficiosas (1)	2	3	4	Extremadamente beneficiosas (5)
○	○	○	○	○

[PRG: If answer 2 through 5 ask:] **Por favor dinos cuáles crees que sean los beneficios de las pruebas genéticas para niños con cáncer:** [PRG: FREE TEXT]

26. En una escala del 1 al 5, ¿qué tan riesgosas crees que son las pruebas genéticas para niños con cáncer?

Nada riesgosas (1)	2	3	4	Extremadamente riesgosas (5)
○	○	○	○	○

[PRG: If answer 2 through 5 ask:] **Por favor dinos cuáles crees que sean los riesgos de las pruebas genéticas para niños con cáncer:** [PRG: FREE TEXT]

27. Por favor elije la descripción que más se acerque a lo que piensas sobre las pruebas genéticas para niños con cáncer.

Hay más beneficios que riesgos.	Hay la misma cantidad de beneficios y de riesgos.	Hay más riesgos que beneficios.
○	○	○

Las siguientes preguntas son sobre tu experiencia con pruebas genéticas antes de estar en el Estudio KidsCanSeq.

28. ¿Quién en tu familia ha tenido pruebas genéticas? Marca todas las que se correspondan.

- ☐ Yo
- ☐ El otro padre biológico de mi hijo(a)
- ☐ Mi hijo(a) que participa en KidsCanSeq
- ☐ Mis otros hijos
- ☐ Nadie en mi familia inmediata ha tenido pruebas genéticas

[PRG: For each response selected in above Q, show next 4 Qs. If select “Nadie en mi familia inmediata ha tenido pruebas genéticas” then skip next 4 Qs:]

29. ¿Por qué [PRG: **tú has** OR **el otro padre biológico de tu hijo(a) ha** OR **tu hijo(a) que participa en KidsCanSeq ha** OR **tus otros hijos han**] **tenido pruebas genéticas? Marca todas las que se correspondan.**

- ☐ Por razones médicas (por ejemplo, por alguna condición médica particular que esta persona tiene o que son frecuentes en la familia)
- ☐ Prueba prenatal [PRG: don’t show if “Mi hijo(a) que participa en KidsCanSeq” chosen above]
- ☐ Para saber de dónde viene mi familia (ascendencia)
- ☐ Para personalizar la medicación utilizando información genética

☐ Para saber quién es el padre de mi hijo(a) (paternidad)
☐ Para otro estudio de investigación
☐ Otro, por favor descríbelo: [FREE TEXT]

30. ¿Qué tipo de prueba genética se realizó? [PRG: FREE TEXT]

31. ¿Cuándo se realizó esta prueba genética? [PRG: YYYY] (AAAA)

32. En una escala del 1 al 5, ¿qué tan útil fue el resultado de la prueba?

Nada útil (1)	2	3	4	Extremadamente útil (5)
○	○	○	○	○

Por favor dinos de qué manera el resultado de la prueba fue útil o no para ti: [PRG: FREE TEXT]

Las siguientes preguntas son para ayudarnos a saber más de cómo las personas entienden esta información. Saber lo que prefieres y necesitas nos ayudara a crear mejores materiales para estudios en el futuro.

33. ¿Con qué frecuencia necesitas que alguien (como un familiar, amigo, ayudante, empleado del hospital o clínica) te ayude a leer materiales médicos?

○ Siempre
○ Frecuentemente
○ Algunas veces
○ Ocasionalmente
○ Nunca

34. ¿Con qué frecuencia se te hace difícil aprender sobre tus condiciones médicas porque se te hace difícil entender la información escrita?

○ Siempre
○ Frecuentemente
○ Algunas veces
○ Ocasionalmente
○ Nunca

35. ¿Con qué frecuencia se te dificulta entender lo que te dicen sobre tu condición médica?

○ Siempre
○ Frecuentemente
○ Algunas veces
○ Ocasionalmente
○ Nunca

36. ¿Qué tan seguro te sientes llenando cuestionarios médicos sin ayuda de nadie?

- ○ Extremadamente
- ○ Bastante
- ○ Regular
- ○ Un poco
- ○ Nada

Por favor evalúate tú mismo/a en las siguientes escalas.

37. ¿Qué tan bueno eres trabajando con fracciones o quebrados?

Nada bueno (1)	2	3	4	5	Extremadamente bueno (6)
○	○	○	○	○	○

38. ¿Qué tan bueno eres para calcular cuánto costaría una camisa si tiene un 25% de descuento?

Nada bueno (1)	2	3	4	5	Extremadamente bueno (6)
○	○	○	○	○	○

39. ¿Con qué frecuencia se te hace útil la información numérica?

Nunca (1)	2	3	4	5	Muy Frecuentemente (6)
○	○	○	○	○	○

Hay muchas razones por las cuales no puedas llevar a tu hijo(a) al médico. Nos gustaría saber si alguna de estas situaciones te ha aplicado a ti.

40. ¿En los últimos 12 meses ha habido alguna ocasión en que querías o necesitabas que tu hijo(a) viera a un médico o a un profesional de la salud, pero no lo hiciste?

- ○ Sí
- ○ No

41. [PRG: if “Sí” to above:] **¿Por qué tu hijo(a) no vio al médico o profesional de la salud cuando tú querías o necesitabas que lo viera, en el último año? Marca todas las que apliquen.**

- ☐ No tenía dinero.

- ☐ Era demasiado difícil llegar hasta allí.
- ☐ No me gusta ir al doctor, y evito hacerlo.
- ☐ No quería que me dieran malas noticias.
- ☐ No tenía tiempo.
- ☐ Decidí resolver el problema yo solo.
- ☐ Decidí esperar para ver si el problema se resolvía solo.
- ☐ El doctor no podía ver mi hijo(a).
- ☐ La compañía de seguro no aprobó, cubrió o pagó por el cuidado médico.
- ☐ El doctor se rehusó a aceptar el plan del seguro.
- ☐ No pude conseguir tiempo libre de mi trabajo.
- ☐ No sabía dónde ir para obtener cuidado médico.
- ☐ Me negaron los servicios.
- ☐ No pude obtener cuidado para niño.
- ☐ La pandemia de COVID-19 (nuevo coronavirus) [PRG: if selected: Por favor descríbelo: [PRG: FREE TEXT]
- ☐ Otro (por favor descríbelo): [PRG: FREE TEXT]

42. ¿Cuál es tu fecha de nacimiento? [PRG: MM/DD/YYYY]

43. ¿Cuál es el género de tu hijo(a) que participa en KidsCanSeq?

- ○ Masculino
- ○ Femenino
- ○ Prefiero describirlo yo: [PRG: FREE TEXT]
- ○ Prefiero no decirlo

44. ¿Cuál es tu género?

- ○ Masculino
- ○ Femenino
- ○ Prefiero describirlo yo: [PRG: FREE TEXT]
- ○ Prefiero no decirlo

45. ¿Qué categoría o categorías se describen mejor tu hijo(a) que participa en KidsCanSeq? Marca todas las que se correspondan.

- ☐ Indio de Estados Unidos, indígena o indio nativo de Estados Unidos, o indígena nativo de Alaska
- ☐ Asiático
- ☐ Negro o africano-americano
- ☐ Indígena nativo de Hawái o de las islas del Pacífico
- ☐ Blanco o europeo-americano
- ☐ Del medio Oriente, norte de África, o mediterráneo
- ☐ Hispano o latino

¿Cuál de los siguientes mejor describe su herencia hispana o latina? Por favor marca sólo una.

Argentino, Beliceño, Boliviano, Chileno, Colombiano, Costarricense, Cubano, Dominicano,
Ecuatoriano, Guatemalteco, Hondureño, Mexicano, Nicaragüense, Panameño, Paraguayo,
Peruano, Puertorriqueño, Salvadoreño, Español, Uruguayo, Venezolano, Más de una
herencia (por favor especificar cuáles)**,** Otra (Por favor descríbelo): [FREE TEXT]]

- ☐ Prefiero no contestar
- ☐ No sé/ninguna de estas categorías se describe completamente mi hijo(a) que participa en KidsCanSeq

46. ¿Qué categoría o categorías te describen mejor? Marca todas las que te correspondan.

- ☐ Indio de Estados Unidos, indígena o indio nativo de Estados Unidos, o indígena nativo de Alaska
- ☐ Asiático
- ☐ Negro o africano-americano
- ☐ Indígena nativo de Hawái o de las islas del Pacífico
- ☐ Blanco o europeo-americano
- ☐ Del medio Oriente, norte de África, o mediterráneo
- ☐ Hispano o latino

¿Cuál de los siguientes mejor describe tu herencia hispana o latina? Por favor marca sólo una.

Argentino, Beliceño, Boliviano, Chileno, Colombiano, Costarricense, Cubano, Dominicano,
Ecuatoriano, Guatemalteco, Hondureño, Mexicano, Nicaragüense, Panameño, Paraguayo,
Peruano, Puertorriqueño, Salvadoreño, Español, Uruguayo, Venezolano, Más de una
herencia (por favor especificar cuáles)**,** Otra (Por favor descríbelo): [FREE TEXT]]

- ☐ Prefiero no contestar
- ☐ No sé/ninguna de estas categorías me describe completamente

47. ¿Cuál de los siguientes mejor describen la variedad/dialecto del español que tú hablas?

- ○ Mexicano
- ○ América Central (Belice, Costa Rica, Guatemala, Honduras, Nicaragua, El Salvador)
- ○ Caribeño (Cuba, Venezuela, Puerto Rico, República Dominicana, Panamá, Colombia caribeña, México caribeño)
- ○ Andino-Pacífico (Colombia, Perú, Ecuador, Bolivia occidental, Venezuela Andina)
- ○ Rioplatense (Argentina, Uruguay, Paraguay, Bolivia oriental)
- ○ Chileno
- ○ Ibérico (España)
- ○ Otra (Por favor descríbelo): [PRG: FREE TEXT]

48. ¿También hablas inglés?

- ○ Sí [PRG: If selected, show next 2 Qs]
- ○ No

49. ¿Qué tan bien hablas inglés?

- ○ Hablo inglés perfectamente bien (Soy bilingüe o un hablante nativo de inglés)
- ○ Muy bien
- ○ Bien
- ○ No lo hablo bien

50. ¿En qué idioma prefieres hablar con los doctores de tu hijo(a)?

- ○ Inglés
- ○ Español
- ○ Me siento igual de cómodo hablando en inglés o en español sobre la atención médica de mi hijo(a)

51. ¿Cuál de los siguientes mejor lo/a describen a ti?

- ○ Casado/a
- ○ Viudo/a
- ○ Divorciado/a
- ○ Separado/a
- ○ Nunca casado/a
- ○ Viviendo con una pareja

52. En una escala del 1 al 5, ¿qué tan importante es la <u>religión</u> o la <u>espiritualidad</u> en tu vida?

Nada importante (1)	2	3	4	Extremadamente importante (5)
○	○	○	○	○

53. ¿Cuál fue el nivel <u>más alto</u> de estudios que completaste, o el <u>grado o título</u> más alto que recibiste?

- ○ Secundaria/middle school o menos (menos que el 9° grado)
- ○ Algo de preparatoria/high school (del 9° al 12° grado), sin graduarse
- ○ Graduado de preparatoria/high school (diploma o GED o equivalente)
- ○ Algo de estudios después de preparatoria/high school (universidad o escuela ocupacional, técnica, o vocacional), sin graduarse o recibir título
- ○ Diplomado (curso de 2 años) a nivel universitario, o completado un programa ocupacional, técnico o vocacional, recibiendo un grado o título.
- ○ Licenciatura (en inglés, por ejemplo BA, AB, BS)
- ○ Estudios de posgrado o profesionales (por ejemplo, maestría o doctorado)

54. **¿Cuál fue el ingreso total de tu familia (antes de los impuestos) del año pasado, incluyendo todas las fuentes de ingresos?**
    - ○ Menos de $20,000
    - ○ $20,000 a $39,999
    - ○ $40,000 a $59,999
    - ○ $60,000 a $79,999
    - ○ $80,000 a $99,999
    - ○ $100,000 a $139,999
    - ○ $140,000 o más

55. **¿A cuántas personas (niños y adultos) mantuvo este ingreso el año pasado?** [PRG: numerical field, 1-20 valid]

56. **¿Antes de enfermarse, estaba tu hijo(a) viviendo en los Estados Unidos?**
    - ○ Sí
    - ○ No [PRG: if selected, don't ask next Q and ask:] ¿Dónde vivía tu hijo(a)? [PRG: FREE TEXT]

57. [PRG: If "sí" selected above]: **Antes de enfermarse, ¿cuál era el código postal de donde tu hijo(a) vivía?** [PRG: FREE TEXT]

58. **¿Tiene tu hijo(a) algún tipo de aseguranza o seguro médico, o algún tipo de plan de cobertura médica? (Incluye aseguranzas/seguros que sean a través de tu trabajo, o que tengas a través de programas de gobierno, como Medicare o Medicaid, que te dan atención médica o que ayudan a pagar gastos médicos).**
    - ○ Sí
    - ○ No

59. [PRG: if "Sí" to above:] **¿Qué tipo o tipos de aseguranza o seguro de cobertura médica tiene tu hijo(a)? Marca todas las que apliquen.**
    - ○ Aseguranza/seguro privado, a través del trabajo
    - ○ Aseguranza/seguro privado, que compras directamente
    - ○ Plan de gobierno/aseguranza publica, Medicare
    - ○ Plan de gobierno/aseguranza publica, Medicaid
    - ○ Plan de gobierno, seguro/aseguranza médica militar como TRICARE y CHAMPVA
    - ○ Plan de gobierno o del estado, Children's Health Insurance Plan (CHIP)
    - ○ Otros tipos de aseguranzas/seguros (Por favor descríbelo): [PRG: FREE TEXT]

60. **¿Tienes algún tipo de aseguranza o seguro médico, o algún tipo de plan de cobertura médica? (Incluye aseguranzas/seguros que sean a través de tu trabajo, o que tengas a través de programas de gobierno, como Medicare o Medicaid, que te dan atención médica o que ayudan a pagar gastos médicos).**
    - ○ Sí

- ○ No

61. [PRG: if “Sí” to above:] **¿Qué tipo o tipos de aseguranza o seguro de cobertura médica tienes? Marca todas las que apliquen.**
  - ○ Aseguranza/seguro privado, a través del trabajo
  - ○ Aseguranza/seguro privado, que compras directamente
  - ○ Plan de gobierno/aseguranza publica, Medicare
  - ○ Plan de gobierno/aseguranza publica, Medicaid
  - ○ Plan de gobierno, seguro/aseguranza médica militar como TRICARE y CHAMPVA
  - ○ Plan de gobierno o del estado, Children’s Health Insurance Plan (CHIP)
  - ○ Otros tipos de aseguranzas/seguros (Por favor descríbelo): [PRG: FREE TEXT]

En esta última sección, nos gustaría conocer la información sobre el historial de salud de los familiares biológicos de tu hijo(a).

62. ¿Eres el padre/madre biológico de tu hijo(a)?
  - ○ Sí, yo soy la madre biológica de mi hijo(a). [PRG: if selected direct to complete biological mother information but don’t ask nombre, apellido, sexo, edad, or con vida o fallecido, and remove “no se” option from Historial de Cancer]
  - ○ Sí, yo soy el padre biológico de mi hijo(a) [PRG: if selected, direct to complete biological father information but don’t ask nombre, apellido, sexo, edad, or con vida o fallecido, and remove “no se” option from Historial de Cancer]
  - ○ No, no soy el padre/madre biológico de mi hijo(a) [PRG: if selected, show Q64]

63. [PRG: if either “Sí” response selected in Q62] **¿Conoces alguna información sobre el historial de salud del otro padre biológico de tu hijo(a)?**
  - ○ Sí [PRG: if selected, direct to complete health history information for other biological parent depending on Q62 (if mother taking survey then give Qs about father, and vice versa)]
  - ○ No [PRG: if selected, skip to Q65]

64. ¿Conoces alguna información sobre el historial de salud del otro padre biológico de tu hijo(a)? Marca todas las que apliquen.
  - ☐ Sí, madre biológica [PRG: if selected, direct to complete “madre biológica” information]
  - ☐ Sí, padre biológico [PRG: if selected, direct to complete “padre biológico” information]
  - ○ No tengo ninguna información sobre los padres biológicos de mi hijo(a) [PRG: if selected, don’t allow selection of other options and don’t ask Qs about “padres biológicos”]

Padres biológicos

	Madre biológica	Padre biológico
Apellido:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Nombre:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Sexo:	[PRG: DROPDOWN LIST, values: Masculino, Femenino, Otro]	[PRG: DROPDOWN LIST, values: Masculino, Femenino, Otro]
Edad:	[PRG: numerical field]	[PRG: numerical field]
¿Con vida o fallecido?	[PRG: Options: Con vida, Fallecido, No sé]	[PRG: Options: Con vida, Fallecido, No sé]
[PRG: If “Fallecido”:] Edad al fallecer:	[PRG: numerical field]	[PRG: numerical field]
[PRG: If “Fallecido”:] Causa de muerte:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
¿Historial de cáncer?	[PRG: Options: Sí, No, No sé]	[PRG: Options: Sí, No, No sé]
[PRG: If “Sí” to Historial de cáncer:] Diagnóstico de tipo de cáncer:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
[PRG: If “Sí” to Historial de cáncer:] Edad cuando se diagnosticó cáncer:	[PRG: numerical field]	[PRG: numerical field]

65. ¿Tiene tu hijo(a) plenos hermanos (hermanos que comparten la misma madre y el mismo padre biológico)?

- ○ Sí [PRG: if selected, show:] **¿Cuántos?** [PRG: numerical field]
- ○ No
- ○ No sé

66. [PRG: if “Sí” to above, show:] **Por favor cuéntanos sobre los plenos hermanos de tu hijo(a).**

[PRG: questions should appear for however many siblings selected in previous Q]

	Pleno hermano 1	Pleno hermano 2
Apellido:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Nombre:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Sexo:	[PRG: DROPDOWN LIST, values: Masculino, Femenino, Otro]	[PRG: DROPDOWN LIST, values: Masculino, Femenino, Otro]
Edad:	[PRG: numerical field]	[PRG: numerical field]
¿Es este niño/a adoptado?	[PRG: DROPDOWN LIST, values: Sí, No]	[PRG: DROPDOWN LIST, values: Sí, No]

¿Con vida o fallecido?	[PRG: Options: Con vida, Fallecido, No sé]	[PRG: Options: Con vida, Fallecido, No sé]
[PRG: If "Fallecido":] Edad al fallecer:	[PRG: numerical field]	[PRG: numerical field]
[PRG: If "Fallecido":] Causa de muerte:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
¿Historial de cáncer?	[PRG: Options: Sí, No, No sé]	[PRG: Options: Sí, No, No sé]
[PRG: If "Sí" to Historial de cáncer: Diagnóstico de tipo de cáncer:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
[PRG: If "Sí" to Historial de cáncer: Edad cuando se diagnosticó cáncer:	[PRG: numerical field]	[PRG: numerical field]

67. ¿Tiene tu hijo(a) medio hermanos relacionados a través de [PRG: if "madre biológica" selected in Q62, then: "**ti"** otherwise: "**su madre biológica"]?**

- ○ Sí [PRG: if selected, show:] **¿Cuántos?** [PRG: numerical field]
- ○ No
- ○ No sé

68. [PRG: if "Sí" to above, show:] **Por favor cuéntanos sobre los medios hermanos de tu hijo(a), relacionados a través de** [PRG: if "madre biológica" selected in Q62 then: **"ti**" otherwise: **"su madre biológica.**"]

[PRG: Qs should appear for however many half siblings selected in previous Q]

	Maternal medio hermano 1	**Maternal medio hermano 2**
Apellido:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Nombre:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Sexo:	[PRG: DROPDOWN LIST, values: Masculino, Femenino, Otro]	[PRG: DROPDOWN LIST, values: Masculino, Femenino, Otro]
Edad:	[PRG: numerical field]	[PRG: numerical field]
¿Es este niño/a adoptado?	[PRG: DROPDOWN LIST, values: Sí, No]	[PRG: DROPDOWN LIST, values: Sí, No]
¿Con vida o fallecido?	[PRG: Options: Con vida, Fallecido, No sé]	[PRG: Options: Con vida, Fallecido, No sé]
[PRG: If "Fallecido":] Edad al fallecer:	[PRG: numerical field]	[PRG: numerical field]
[PRG: If "Fallecido":] Causa de muerte:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
¿Historial de cáncer?	[PRG: Options: Sí, No, No sé]	[PRG: Options: Sí, No, No sé]

[PRG: If "Sí" to Historial de cáncer:] Diagnóstico de tipo de cáncer:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
[PRG: If "Sí" to Historial de cáncer:] Edad cuando se diagnosticó cáncer:	[PRG: numerical field]	[PRG: numerical field]

69. **¿Tiene su hijo(a) medio hermanos relacionados a través de** [PRG: if "padre biológico" selected in Q62, then: "**ti"** otherwise "**su padre biológico"]?**
    - ○ Sí [PRG: if selected, show:] **¿Cuántos?** [PRG: numerical field]
    - ○ No
    - ○ No sé

70. [PRG: if "Sí" to above, show:] **Por favor cuéntenos sobre los medio hermanos de tu hijo(a), relacionados a través de** [PRG: if "padre biológico" selected in Q62 then: **"ti**" otherwise: **"su padre biológico."**]

[PRG: Qs should appear for however many half siblings selected in previous Q]

	Paternal medio hermano 1	**Paternal medio hermano 2**
Apellido:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Nombre:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
Sexo:	[PRG: DROPDOWN LIST, values: Masculino, Femenino, Otro]	[PRG: DROPDOWN LIST, values: Masculino, Femenino, Otro]
Edad:	[PRG: numerical field]	[PRG: numerical field]
¿Es este niño/a adoptado?	[PRG: DROPDOWN LIST, values: Sí, No]	[PRG: DROPDOWN LIST, values: Sí, No]
¿Con vida o fallecido?	[PRG: Options: Con vida, Fallecido, No sé]	[PRG: Options: Con vida, Fallecido, No sé]
[PRG: If "Fallecido":] Edad al fallecer:	[PRG: numerical field]	[PRG: numerical field]
[PRG: If "Fallecido":] Causa de muerte:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
¿Historial de cáncer?	[PRG: Options: Sí, No, No sé]	[PRG: Options: Sí, No, No sé]
[PRG: If "Sí" to Historial de cáncer:] Diagnóstico de tipo de cáncer:	[PRG: FREE TEXT]	[PRG: FREE TEXT]
[PRG: If "Sí" to Historial de cáncer:] Edad cuando se diagnosticó cáncer:	[PRG: numerical field]	[PRG: numerical field]

¡Gracias por completar esta encuesta del Estudio KidsCanSeq!

Appendix G: Parent Decliner Survey (English)

Thank you for taking the time to take this survey.

We want to know why some people choose not to participate in the **KidsCanSeq Study**. This survey is optional. You can skip any questions that you do not want to answer. You can stop at any time. Your child's care will not change based on how you answer these questions or if you do not want to take this survey.

We will also ask you some basic questions like your age, race/ethnicity, and gender.

This survey should take **5 minutes** to complete.

If you have questions about this study, you can call Robin Raesz-Martinez at (832)-824-7822. If you want to talk to someone not involved in this study or if you have concerns or complaints, you can call the Baylor College of Medicine IRB at (713)-798-6970.

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

1. **Please tell us why you decided not to join this study:** [PRG: FREE TEXT]

2. **This list is from other patients/parents who decided not to join studies like this one. Did any of these reasons affect your decision not to join this study? Please choose up to three (3) reasons.**
   - ☐ The things I/my child need to do to be in the study didn't work well for me
   - ☐ My child's current health condition is all I want to focus on right now
   - ☐ I don't want genetic research results from this study
   - ☐ I'm worried about how I will cope with the genetic information I might receive
   - ☐ I have concerns about my/my child's privacy
   - ☐ I am not interested in participating in research

Now we would like to know a little more about you and your child.

3. **What year were you born?** [PRG: YYYY]

4. **What is your gender?**
   - ○ Male
   - ○ Female
   - ○ I prefer to self-describe: [PRG: FREE TEXT]
   - ○ I prefer not to say

5. **Do you speak another language besides English?**
   - ○ Yes [PRG: If selected, show next 2 Qs]
   - ○ No

6. **How well do you speak English?**

- ○ Native English-speaker
- ○ Very well
- ○ Well
- ○ Not well

7. **What language do you prefer to speak with your child's doctors?**
   - ○ English
   - ○ Another language
   - ○ I am equally comfortable discussing my child's medical care in both English and another language

8. [PRG: If "another language" selected in above Q:] **Please tell us which language you prefer to speak with your child's doctors:** [PRG: DROPDOWN LIST:] Spanish, Vietnamese, Chinese (Mandarin, Cantonese, or other Chinese language), Tagalog, German, French, Korean, Russian, Arabic, Other (please describe): [PRG: FREE TEXT]

9. **What category or categories best describe your child? Please check all that apply.**
   - ☐ American Indian, Native American, or Alaska Native
   - ☐ Asian
   - ☐ Black or African American
   - ☐ Native Hawaiian or Pacific Islander
   - ☐ White or European American
   - ☐ Middle Eastern or North African/Mediterranean
   - ☐ Hispanic or Latino
     [if selected]: **Which of these best describes your child's Hispanic or Latino heritage? Please choose one.** [PRG: DROPDOWN LIST: Argentine, Belizean, Bolivian, Chilean, Colombian, Costa Rican, Cuban, Dominican, Ecuadorian, Guatemalan, Honduran, Mexican, Nicaraguan, Panamanian, Paraguayan, Peruvian, Puerto Rican, Salvadoran, Spaniard, Uruguayan, Venezuelan, More than one heritage (please describe which ones): [FREE TEXT], Other (please describe): [FREE TEXT]]
   - ☐ I prefer not to answer
   - ☐ Unknown/none of these fully describe my child

10. **What category or categories best describe you? Please check all that apply.**
    - ☐ American Indian, Native American, or Alaska Native
    - ☐ Asian
    - ☐ Black or African American
    - ☐ Native Hawaiian or Pacific Islander
    - ☐ White or European American
    - ☐ Middle Eastern or North African/Mediterranean
    - ☐ Hispanic or Latino
      [if selected]: **Which of these best describes your Hispanic or Latino heritage? Please choose one.** [PRG: DROPDOWN LIST: Argentine, Belizean,

Bolivian, Chilean, Colombian, Costa Rican, Cuban, Dominican, Ecuadorian, Guatemalan, Honduran, Mexican, Nicaraguan, Panamanian, Paraguayan, Peruvian, Puerto Rican, Salvadoran, Spaniard, Uruguayan, Venezuelan, More than one heritage (please describe which ones): [FREE TEXT], Other (please describe): [FREE TEXT]]

- ☐ I prefer not to answer
- ☐ Unknown/none of these fully describe me

11. What is the highest grade level of school you completed or the highest degree you received?

- ○ Less than high school (less than 9th grade)
- ○ Some high school (9th to 12th grade), no diploma
- ○ High school graduate (diploma or GED or equivalent)
- ○ Some college or occupational, technical, or vocational training, no degree or certificate
- ○ Associate (2-year) college degree, or completed occupational, technical, or vocational program and received degree or certificate
- ○ Bachelor's degree (for example: BA, AB, BS)
- ○ Graduate or professional degree (for example: MA, MBA, JD, MD, PhD)

12. What was your household's total family income (before taxes) from all sources in the last year? Please select one.

- ○ Less than $20,000
- ○ $20,000 $39,999
- ○ $40,000 to $59,999
- ○ $60,000 to $79,999
- ○ $80,000 to $99,999
- ○ $100,000 to $139,999
- ○ $140,000 or more

13. How many people (children and adults) were supported by this income in the last year? [PRG: dropdown list options 1-20]

14. Is your child covered by health insurance or some other kind of health care plan? (Include health insurance obtained through employment or purchased directly as well as government programs like Medicare and Medicaid that provide medical care or help pay medical bills).

- ○ No
- ○ Yes

15. [PRG: if yes:] **What kind or kinds of health insurance or health care coverage does your child have? (Check all that apply)**

- ☐ Private health insurance, employment based
- ☐ Private health insurance, directly purchased

- ☐ Government plan, Medicare
- ☐ Government plan, Medicaid
- ☐ Government plan, Military health care such as TRICARE and CHAMPVA
- ☐ Government/State plan, Children's Health Insurance Plan (CHIP)
- ☐ Other type of insurance (please describe): [PRG: FREE TEXT]

16. **Are you covered by health insurance or some other kind of health care plan? (Include health insurance obtained through employment or purchased directly as well as government programs like Medicare and Medicaid that provide medical care or help pay medical bills).**
    - ○ No
    - ○ Yes

17. [PRG: if yes:] **What kind or kinds of health insurance or health care coverage do you have? (Check all that apply)**
    - ☐ Private health insurance, employment based
    - ☐ Private health insurance, directly purchased
    - ☐ Government plan, Medicare
    - ☐ Government plan, Medicaid
    - ☐ Government plan, Military health care such as TRICARE and CHAMPVA
    - ☐ Government/State plan, Children's Health Insurance Plan (CHIP)
    - ☐ Other type of insurance (Please describe): [PRG: FREE TEXT]

Thank you for completing this survey!

Appendix H: Parent Decliner Survey (Spanish)

Gracias por tomarse el tiempo de hacer esta encuesta.

Queremos saber por qué algunas personas eligen no participar en el **Estudio de KidsCanSeq**. Esta encuesta es opcional. Puede saltar cualquier pregunta que usted no desee responder. Puede detenerse en cualquier momento. El cuidado de su hijo o hija no cambiará basado en cómo usted responda a estas preguntas o si no quiere hacer esta encuesta.

También le haremos algunas preguntas básicas tales como su edad, raza/etnia, y género.

Esta encuesta solo le tomará **5 minutos** para completarla.

Si tiene alguna pregunta sobre este estudio, puede comunicarse con Robin Raesz-Martinez en el (832)-824-7822. Si desea hablar con alguien que no esté involucrado con este estudio o si tiene preocupaciones o quejas, puede llamar a la IRB de Baylor College of Medicine en el (713) 798-6970.

Ahora nos gustaría saber un poco más sobre usted y su hijo o hija. Usamos “tú” en esta encuesta para refiere a usted, el padre o la madre del paciente.

[PRG: don’t show question numbers is survey]

1. **Por favor, dinos por qué decidiste no participar en este estudio:** [PRG: FREE TEXT]

2. **Esta es una lista de razones por las que otros pacientes han decidido no participar en estudios como éste. ¿Piensas que alguna de estas razones afectó tu decisión de no participar en este estudio? Por favor escoge un máximo de tres (3) razones.**
   - ☐ No quería hacer las cosas que yo/mi hijo tenía que hacer para estar en el estudio.
   - ☐ Me preocupaba mi privacidad
   - ☐ No me interesa participar en investigaciones
   - ☐ En este momento, solo quiero enfocarme en mi salud/la salud de mi hijo
   - ☐ No quiero los resultados genéticos del estudio
   - ☐ Me preocupa cómo iba a sobrellevar la información genética que pudieran darme

Ahora nos gustaría saber un poco más sobre tú y tu hijo o hija.

3. **¿En qué año naciste?** [PRG: YYYY]

4. **¿Cuál es tu género?**
   - ○ Masculino
   - ○ Femenino
   - ○ Prefiero describirlo yo: [PRG: FREE TEXT]
   - ○ Prefiero no decirlo

5. **¿También hablas inglés?**
   - ○ Sí [PRG: If selected, show next 2 Qs]

- ○ No

6. **¿Qué tan bien hablas inglés?**
   - ○ Hablo inglés perfectamente bien (Soy bilingüe o una hablante nativa de inglés)
   - ○ Muy bien
   - ○ Bien
   - ○ No lo hablo bien

7. **¿En qué idioma prefieres hablar con los doctores de tu hijo o hija?**
   - ○ Inglés
   - ○ Español
   - ○ Me siento igual de cómodo hablando en inglés o en español sobre la atención médica de mi hijo o hija

8. **¿Qué categoría o categorías se describen mejor tu hijo o hija? Marca todas las que se correspondan.**
   - ☐ Indio de Estados Unidos, indígena o indio nativo de Estados Unidos, o indígena nativo de Alaska
   - ☐ Asiático
   - ☐ Negro o africano-americano
   - ☐ Indígena nativo de Hawái o de las islas del Pacífico
   - ☐ Blanco o europeo-americano
   - ☐ Del medio Oriente, norte de África, o mediterráneo
   - ☐ Hispano o latino

     ¿Cuál de los siguientes mejor describe su herencia hispana o latina?

     Argentino, Beliceño, Boliviano, Chileno, Colombiano, Costarricense, Cubano, Dominicano,

     Ecuatoriano, Guatemalteco, Hondureño, Mexicano, Nicaragüense, Panameño, Paraguayo,

     Peruano, Puertorriqueño, Salvadoreño, Español, Uruguayo, Venezolano, Más de una

     herencia (por favor especificar cuáles)**,** Otra (Por favor descríbelo): [FREE TEXT]]
   - ☐ Prefiero no contestar
   - ☐ No sé/ninguna de estas categorías se describe completamente mi hijo o hija

9. **¿Qué categoría o categorías te describen mejor? Marca todas las que te correspondan.**
   - ☐ Indio de Estados Unidos, indígena o indio nativo de Estados Unidos, o indígena nativo de Alaska
   - ☐ Asiático
   - ☐ Negro o africano-americano
   - ☐ Indígena nativo de Hawái o de las islas del Pacífico
   - ☐ Blanco o europeo-americano
   - ☐ Del medio Oriente, norte de África, o mediterráneo
   - ☐ Hispano o latino

¿Cuál de los siguientes mejor describe tu herencia hispana o latina?

Argentino, Beliceño, Boliviano, Chileno, Colombiano, Costarricense, Cubano, Dominicano,

Ecuatoriano, Guatemalteco, Hondureño, Mexicano, Nicaragüense, Panameño, Paraguayo,

Peruano, Puertorriqueño, Salvadoreño, Español, Uruguayo, Venezolano, Más de una

herencia (por favor especificar cuáles)**,** Otra (Por favor descríbelo): [FREE TEXT]]

- ☐ Prefiero no contestar
- ☐ No sé/ninguna de estas categorías me describe completamente

10. **¿Cuál fue el nivel <u>más alto</u> de estudios que completaste, o el <u>grado o título</u> más alto que recibiste?**
    - ○ Secundaria/middle school o menos (menos que el 9° grado)
    - ○ Algo de preparatoria/high school (del 9° al 12° grado), sin graduarse
    - ○ Graduado de preparatoria/high school (diploma o GED o equivalente)
    - ○ Algo de estudios después de preparatoria/high school (universidad o escuela ocupacional, técnica, o vocacional), sin graduarse o recibir título
    - ○ Diplomado (curso de 2 años) a nivel universitario, o completado un programa ocupacional, técnico o vocacional, recibiendo un grado o título.
    - ○ Licenciatura (en inglés, por ejemplo BA, AB, BS)
    - ○ Estudios de posgrado o profesionales (por ejemplo, maestría o doctorado)

11. **¿Cuál fue el ingreso total de tu familia (antes de los impuestos) del año pasado, incluyendo todas las fuentes de ingresos?**
    - ○ Menos de $20,000
    - ○ $20,000 a $39,999
    - ○ $40,000 a $59,999
    - ○ $60,000 a $79,999
    - ○ $80,000 a $99,999
    - ○ $100,000 a $139,999
    - ○ $140,000 o más

12. **¿A cuántas personas (niños y adultos) mantuvo este ingreso el año pasado?** [PRG: dropdown list options 1-20]

13. **¿Tu hijo o hija tiene algún tipo de aseguranza o seguro médico, o algún tipo de plan de cobertura médica? (Incluye aseguranzas/seguros que sean a través de tu trabajo, o que tengas a través de programas de gobierno, como Medicare o Medicaid, que te dan atención médica o que ayudan a pagar gastos médicos).**
    - ○ No
    - ○ Sí

14. [PRG: if yes:] **¿Qué tipo o tipos de aseguranza o seguro de cobertura médica tiene tu hijo o hija? Marca todas las que apliquen.**
    - ○ Aseguranza/seguro privado, a través del trabajo

- Aseguranza/seguro privado, que compras directamente
- Plan de gobierno/aseguranza publica, Medicare
- Plan de gobierno/aseguranza publica, Medicaid
- Plan de gobierno, seguro/aseguranza médica militar como TRICARE y CHAMPVA
- Plan de gobierno o del estado, Children's Health Insurance Plan (CHIP)
- Otros tipos de aseguranzas/seguros (Por favor descríbelo): [PRG: FREE TEXT]

15. **¿Tienes algún tipo de aseguranza o seguro médico, o algún tipo de plan de cobertura médica? (Incluye aseguranzas/seguros que sean a través de tu trabajo, o que tengas a través de programas de gobierno, como Medicare o Medicaid, que te dan atención médica o que ayudan a pagar gastos médicos).**
    - No
    - Sí

16. [PRG: if yes:] **¿Qué tipo o tipos de aseguranza o seguro de cobertura médica tienes? Marca todas las que apliquen.**
    - Aseguranza/seguro privado, a través del trabajo
    - Aseguranza/seguro privado, que compras directamente
    - Plan de gobierno/aseguranza publica, Medicare
    - Plan de gobierno/aseguranza publica, Medicaid
    - Plan de gobierno, seguro/aseguranza médica militar como TRICARE y CHAMPVA
    - Plan de gobierno o del estado, Children's Health Insurance Plan (CHIP)
    - Otros tipos de aseguranzas/seguros (Por favor descríbelo): [PRG: FREE TEXT]

¡Gracias por completar esta encuesta!

Appendix I: Parent Post-Disclosure Survey (English)

Thank you for participating in the **KidsCanSeq Study** and for taking time to complete this survey. The purpose of this survey is to understand how parents of children with cancer feel about receiving their child's genetic test results.

Your answers to each question are important to us, but you can skip any questions that you do not want to answer. Your answers to these questions have no effect on your child's clinical care.

This survey should take about **10 minutes** to complete.

If you have questions about this study, you can call Robin Raesz-Martinez at (832)-824-7822. If you want to talk to someone who is not a part of this study or if you have concerns or complaints, you can call the Baylor College of Medicine IRB at (713)-798-6970.

[PRG: Send to ALL Parents of patients who receive a positive germline finding (does not include VUS if sent via letter) and an equal number of parents who received no significant germline or tumor findings.]

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

As a reminder, your child had genetic testing as part of the KidsCanSeq study. You should have received your child's genetic tests results [PRG: **in-person** OR **over the phone** OR **over videoconference** OR **by email and/or mail**]**.**

[PRG: If received results by email/mail:] **Q0. Have you reviewed your child's genetic test results?**

- Yes
- No

[If "Yes" is selected to Q0, then continue to Q1.]

[PRG: If "No" is selected to Q0:] We understand that there are many reasons why you might not have reviewed this information yet. **Q0a. Why haven't you reviewed your child's test results?**

- I didn't receive any results
- I don't plan to review the results
- Other reason [PRG: Free text]

[If "I don't plan to review the results" selected to Q0a, then end the survey with "Thank you!" Survey marked as complete to trigger compensation. Participant can still be sent 6-month follow-up survey.]

[PRG: If "No" to Q0 AND "I didn't receive any results" OR "Other reason" to Q0a, then display the following:

"Thank you for letting us know. If you did not receive your child's study results, or have questions about them before completing this survey, please call the study coordinator, Robin Raesz-Martinez at (832)-824-7822. When you have time, please review your child's results before completing this survey. If you need to exit this page, you can re-enter the survey using the log-in information in the survey invitation email."

Survey ends and reminder sent with link to the survey in 1 week, with regular reminders after. If no responses to additional reminders, survey marked as complete.]

1. **Overall, how satisfied are you with your child's genetic test results?**
   - Very satisfied
   - Somewhat satisfied
   - Somewhat dissatisfied
   - Very dissatisfied

Please tell us more about why you feel this way. [PRG: FREE TEXT]

	Not at all	A little	Somewhat	Well	Very Well
2. How well do you understand your child's test results?	○	○	○	○	○

Please tell us how useful you think your child's test results will be for the following purposes:

	Not at all useful	A little useful	Somewhat useful	Neutral	Useful	Very useful	Extremely useful
3. Use for testing a future pregnancy, if appropriate	○	○	○	○	○	○	○
4. Help me or our family mentally prepare for the future	○	○	○	○	○	○	○
5. Help to better understand my child's health	○	○	○	○	○	○	○
6. Contribute to my child's self-knowledge	○	○	○	○	○	○	○
7. Help me cope with my child's health risks	○	○	○	○	○	○	○
8. Help me feel more in control of my child's health	○	○	○	○	○	○	○
9. Help me feel more in control of my child's life	○	○	○	○	○	○	○
10. Simply to provide information	○	○	○	○	○	○	○
11. Satisfy my curiosity about my child	○	○	○	○	○	○	○
12. Help my child use social programs, like	○	○	○	○	○	○	○

resources and services							
13. Improve communication with my family members	○	○	○	○	○	○	○
14. Feel good about helping the medical community	○	○	○	○	○	○	○
15. Feel good about having information for family members	○	○	○	○	○	○	○
16. Feel good about taking responsibility for my child's health	○	○	○	○	○	○	○

[PRG: if parent received results by email/mail, DO NOT SHOW Qs 17-21]

Please tell us about your experience receiving your child's genetic test results.

	Strongly Disagree	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
17. I was treated with sensitivity and respect.	○	○	○	○	○
18. I felt listened to.	○	○	○	○	○
19. The clinical team checked to make sure I understood the information.	○	○	○	○	○
20. I trust the clinical team.	○	○	○	○	○
21. The clinical team explained complicated topics well.	○	○	○	○	○
22. I got clear, understandable information.	○	○	○	○	○
23. I received too much information to understand.	○	○	○	○	○
24. It was hard to make sense out of the information.	○	○	○	○	○
25. I felt I had the information and support available to me to answer any questions I had after receiving my child's genetic results.	○	○	○	○	○

[PRG: if parent received results by email/mail, DO NOT SHOW Qs 26-30]

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not Applicable
26. I felt comfortable asking questions and voicing my concerns.	○	○	○	○	○	○
27. The clinical team helped me cope with any uncertainty or unknowns.	○	○	○	○	○	○
28. It was hard to ask questions about this information.	○	○	○	○	○	○
29. I felt comfortable talking about sensitive issues or embarrassing subjects with the clinical team.	○	○	○	○	○	○
30. The clinical team noticed when I had problems understanding.	○	○	○	○	○	○
31. I had questions about this information that I was unable to ask.	○	○	○	○	○	○

Think about how you received your child's genetic test results [PRG: **in-person** OR **over the phone** OR **over videoconference** OR **by email and/or mail**]**.**

32. How satisfied were you with receiving your child's genetic test results this way?

- ○ Very satisfied
- ○ Somewhat satisfied
- ○ Somewhat dissatisfied
- ○ Very dissatisfied

[PRG: If select somewhat or very dissatisfied, ask:] **Why were you not satisfied receiving your child's genetic test results this way?** [PRG: FREE TEXT]

33. Would you have preferred to receive your child's genetic test results in a different way?

- ○ Yes
- ○ No

[If yes to above Q:] **Which of the following ways would you have preferred to receive your child's genetic test results?** [PRG: don't show mode by which parent received results as a response option]

- ○ In-person
- ○ Over the phone

- Over a videoconference
- By email and/or mail
- Other, please specify: [PRG: FREE TEXT]

34. Is there anything else you wish you could change about how your child's genetic test results were communicated to you in the KidsCanSeq Study?

- Yes, please explain: [PRG: FREE TEXT]
- No

[PRG: only show if parent received results via telemedicine] **We would like to ask about your experience receiving your child's genetic test results over video conference with the clinical team.**

35. Please tell us if you had any of the following problems when communicating with the clinical team during that session. Please check all that apply.

- □ The sound didn't work or was hard to hear
- □ The video didn't work or was hard to see
- □ The call dropped
- □ I didn't talk as much as I would have in person
- □ I couldn't ask as many questions as I would have in person
- □ The conversation was awkward or not natural
- □ The conversation was not as friendly or warm as I would have liked
- □ The clinical team felt too far away
- □ It was difficult to have a personal connection with the clinical team
- □ Other, please specify: [PRG: FREE TEXT]
- □ I did not have any problems communicating with the clinical team over video conference [PRG: if selected, don't allow selection of other options and don't show follow-up Q]

[PRG: for each selected above, ask:] **How much do you feel this negatively impacted your communication with the clinical team during the session?**

- A little
- Somewhat
- A lot

[PRG: only show the next Qs if an interpreter was present for disclosure] **An interpreter helped the clinical team give you your child's genetic test results.**

36. Overall, how satisfied were you with the interpreter?

- Very satisfied
- Satisfied
- Dissatisfied
- Very dissatisfied

Please explain why you felt this way? [PRG: FREE TEXT]

37. How would you rate the quality of interpretation?

- Very poor
- Poor
- Good
- Very good

[PRG: If select “very poor” or “poor”, ask:] **Please explain why you felt this way.**
[PRG: FREE TEXT]

[PRG: if select “very poor” or “poor” above, ask:] **How much do you feel this negatively impacted your communication with the clinical team during the session?**

- Not at all
- A little
- Somewhat
- A lot

Please think about both the interpreter and clinical team member(s), such as the genetic counselor(s), who gave you your child’s results.

38. The interpreter and clinical team member(s) worked well together.

- Strongly disagree
- Disagree
- Neither agree nor disagree
- Agree
- Strongly agree

Now, comparing the interpreter to the clinical team:

39. How at ease did you feel with the interpreter and clinical team member(s)?

- I felt MORE at ease with the interpreter than with the clinical team member(s)
- I felt LESS at ease with the interpreter than with the clinical team member(s)
- I felt EQUALLY at ease with BOTH the interpreter and clinical team member(s)
- I did NOT feel at ease with EITHER the interpreter or clinical team member(s)

40. How respected did you feel by the interpreter and clinical team member(s)?

- I felt MORE respected by the interpreter than by the clinical team member(s)
- I felt LESS respected by the interpreter than by the clinical team member(s)
- I felt EQUALLY respected by BOTH the interpreter and clinical team member(s)
- I did NOT feel respected by EITHER the interpreter or clinical team member(s)

41. How well did you feel the interpreter and clinical team member(s) understood your customs or beliefs?

- I felt that the interpreter understood my customs and beliefs BETTER than the clinical team member(s) did
- I felt that the interpreter did NOT understand my customs and beliefs AS WELL as the clinical team member(s) did
- I felt that BOTH the interpreter and clinical team member(s) understood my customs and beliefs equally well
- I felt that NEITHER the interpreter nor the clinical team member(s) understood my customs or beliefs well

42. How much of a personal connection did you feel you had with the interpreter and clinical team member(s)?

- I felt I had MORE of a personal connection with the interpreter than with the clinical team member(s)
- I felt I had LESS of a personal connection with the interpreter than with the clinical team member(s)

- I felt I had a personal connection with BOTH the interpreter and clinical team member(s)
- I felt I did NOT have a personal connection with EITHER the interpreter or clinical team member(s)

Do you have questions about your child's test results? If so, please let us know if you would like a KidsCanSeq Study genetic counselor to call you and go over your questions.

☐ Yes, I would like a KidsCanSeq Study team member to call me

[PRG: If "If yes…" box is checked]: What is the best phone number to call you? [XXX-XXX-XXXX]

You have reached the end of the survey. Are you happy with your answers?

☐ If yes, check this box to complete the survey and receive your compensation.

To submit the survey, please click on the SUBMIT button below. If you need to review or change any answers, you may click on the PREVIOUS button below to go back.

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

Appendix J: Parent Post-Disclosure Survey (Spanish)

Gracias por participar en el **Estudio de KidsCanSeq** y por tomarse el tiempo para completar esta encuesta. El propósito de esta encuesta es entender qué es lo que piensan los padres de niños con cáncer sobre recibir los resultados de las pruebas genéticas de su hijo o hija.

Sus respuestas a cada pregunta son importantes para nosotros, pero puede saltarse cualquier pregunta que no desee responder. Sus respuestas a estas preguntas no tienen ningún efecto en el cuidado clínico de su hijo o hija.

Esta encuesta le tomará aproximadamente **10 minutos** para completarla.

Si tiene alguna pregunta sobre este estudio, puede comunicarse con Robin Raesz-Martinez en el (832)-824-7822. Si desea hablar con alguien que no esté involucrado con este estudio o si tiene preocupaciones o quejas, puede llamar a la IRB de Baylor College of Medicine en el (713) 798-6970.

[PRG: Send to ALL Parents of patients who receive a positive germline finding (does not include VUS if sent via letter) and an equal number of parents who received no significant germline or tumor findings.]

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

Usamos "tú" en esta encuesta para refiere a usted, el padre o la madre del paciente.

Como recordatorio, recibiste los resultados de la prueba genética de tu hijo o hija [PRG: **en persona** OR **por teléfono** OR **por videoconferencia** OR **por email/correo electrónico o por correo**]**.**

[PRG: If received results by email/mail:] **¿Has revisado los resultados de las pruebas genéticas de tu hijo o hija?**

- Sí
- No

[PRG: If "No", this text appears: "Gracias por informarnos y entendemos que este es un tiempo ocupado. Cuando usted tenga tiempo, por favor revise los resultados que se le enviaron antes de completar esta encuesta. Si necesita salir de esta página, puede volver a la encuesta utilizando la información de inicio de sesión en el correo electrónico con la invitación para esta encuesta."]

1. **En general, ¿qué tan satisfecho estás con los resultados de la prueba genética de tu hijo o hija?**
   - Estoy muy satisfecho
   - Estoy algo satisfecho
   - Estoy algo descontento
   - Estoy muy descontento

   Por favor cuéntanos más sobre por qué te sientes de esta manera. [PRG: FREE TEXT]

	Nada	**Un poco**	**Regular**	**Bastante**	**Extremadamente**
2. ¿Qué tan bien entiendes los resultados de las pruebas de tu hijo o hija?	○	○	○	○	○

Por favor dinos qué tan útil crees que los resultados de las pruebas de tu hijo o hija serán para los siguientes propósitos:

	Nada útil	**Casi nada útil**	**Un poco útil**	**Neutro**	**Útil**	**Bastante útil**	**Extremadamente útil**

3. Ayudan a que yo decida si quiero pruebas genéticas para un futuro embarazo, antes de que nazca el bebé	○	○	○	○	○	○	○
4. Ayudan a que yo o mi familia estemos mentalmente preparados para el futuro	○	○	○	○	○	○	○
5. Me ayudan a entender la salud de mi hijo o hija	○	○	○	○	○	○	○
6. Hacen que mi hijo o hija se conozca mejor	○	○	○	○	○	○	○
7. Me ayudan a sobrellevar los riesgos a la salud de mi hijo o hija	○	○	○	○	○	○	○
8. Me hacen sentir que yo controlo la salud de mi hijo o hija	○	○	○	○	○	○	○
9. Me hacen sentir que yo controlo la vida de mi hijo o hija	○	○	○	○	○	○	○
10. Simplemente dan información	○	○	○	○	○	○	○
11. Satisfacen mi curiosidad sobre mi hijo o hija	○	○	○	○	○	○	○
12. Le ayudan a mi hijo o hija a usar programas de recursos y servicios sociales	○	○	○	○	○	○	○
13. Ayudan a mejorar mi comunicación	○	○	○	○	○	○	○

con las personas de mi familia							
14. Me hacen sentir bien de poder ayudar a la comunidad médica	○	○	○	○	○	○	○
15. Me hacen sentir bien de poder dar información a personas de mi familia	○	○	○	○	○	○	○
16. Me hacen sentir bien de hacerme responsable de la salud de mi hijo o hija	○	○	○	○	○	○	○

[PRG: if parent received results by email, DO NOT SHOW Qs 17-21]

Por favor cuéntanos cómo fue tu experiencia de recibir los resultados de las pruebas genéticas de tu hijo o hija.

	Completamente falso	**Falso**	**Ni cierto ni falso**	**Cierto**	**Completamente cierto**
17. Me trataron con sensibilidad y respeto.	○	○	○	○	○
18. Sentí que de verdad me prestaron atención.	○	○	○	○	○
19. El equipo clínico se aseguró de que yo entendiera la información.	○	○	○	○	○
20. Le tengo confianza al equipo clínico.	○	○	○	○	○
21. El equipo clínico pudo explicar bien temas que eran complicados.	○	○	○	○	○
22. Recibí información clara y fácil de entender.	○	○	○	○	○
23. Recibí tanta información que no pude entenderla.	○	○	○	○	○

24. Era difícil entender o encontrarle sentido a la información.	○	○	○	○	○
25. Después de recibir los resultados de la prueba genética de mi hijo o hija, sentí que tenía suficiente información y apoyo para aclarar mis dudas.	○	○	○	○	○

[PRG: if parent received results by email, DO NOT SHOW Qs 26-30]

	Completamente falso	**Falso**	**Ni cierto ni falso**	**Cierto**	**Completamente cierto**	**No Aplica**
26. Me siento cómodo haciendo preguntas y diciendo qué me preocupa.	○	○	○	○	○	○
27. El equipo clínico me ayudó a sobrellevar o lidiar con no saber qué va a pasar.	○	○	○	○	○	○
28. Era difícil hacer preguntas sobre esta información.	○	○	○	○	○	○
29. Me sentí cómodo al hablar con el equipo clínico sobre temas delicados o vergonzosos.	○	○	○	○	○	○
30. El equipo clínico se daba cuenta cuando yo no podía entender algo.	○	○	○	○	○	○
31. Tuve dudas sobre esta información, pero no pude hacer preguntas.	○	○	○	○	○	○

Piensa en la forma en que recibió los resultados de las pruebas genéticas de tu hijo o hija [PRG: **en persona** OR **por teléfono** OR **por videoconferencia** OR **por email/correo electrónico o por correo**]**.**

32. ¿Qué tan satisfecho estás con haber recibido de esa manera los resultados de las pruebas genéticas de tu hijo o hija?

- ○ Estoy muy satisfecho
- ○ Estoy algo satisfecho
- ○ Estoy algo descontento

- Estoy muy descontento

[PRG: If select “estoy algo descontento” or “estoy muy descontento”, ask:] **¿Por qué estás descontento de haber recibido los resultados de las pruebas genéticas de tu hijo o hija de esta manera?** [PRG: FREE TEXT]

33. ¿Hubieras preferido recibir los resultados de las pruebas genéticas de tu hijo o hija de otra manera?

- Sí
- No

[If “Sí” to above Q:] **¿En cuál de las siguientes maneras hubieras preferido recibir los resultados de las pruebas genéticas de tu hijo o hija?** [PRG: don’t show mode by which parent received results as a response option]

- En persona
- Por teléfono
- Por videoconferencia
- Por email/correo electrónico o correo
- De otra manera, por favor especifica: [PRG: FREE TEXT]

34. ¿Hay algo que te hubiera gustado cambiar sobre la manera en que te comunicaron los resultados de las pruebas genéticas de tu hijo o hija en el estudio de KidsCansSeq?

- Sí, por favor explica: [PRG: FREE TEXT]
- No

[PRG: only show if parent received results via telemedicine] **Nos gustaría hacerte algunas preguntas sobre tu experiencia recibiendo los resultados de las pruebas genéticas de tu hijo o hija a través de una videoconferencia con el equipo clínico.**

35. Por favor dinos si tuviste algunos de los siguientes problemas al comunicarte con el equipo clínico durante esa sesión. Marca todas las que apliquen.

- □ El sonido no funcionaba o era difícil escuchar
- □ El video no funcionaba o era difícil de ver
- □ La llamada se interrumpió
- □ No hablé tanto como lo hubiera hecho en persona
- □ No pude hacer tantas preguntas como las que hubiera hecho en persona
- □ La conversación era incómoda o no natural
- □ La conversación no fue tan amistosa o cálida como me hubiera gustado
- □ El equipo clínico se sintió demasiado lejos
- □ Fue difícil tener una conexión personal con el equipo clínico
- □ Otro, por favor descríbelo: [PRG: FREE TEXT]
- □ No tuve ningún problema comunicándome con el equipo clínico a través de una videoconferencia [PRG: if selected, don’t allow selection of other options and don’t show follow-up Q]

[PRG: for each selected above, ask:] **¿Qué tanto sientes tú que esto impactó negativamente en tu comunicación con el equipo clínico durante la sesión?**

- Demasiada
- Suficiente
- Muy poca

[PRG: only show the next Qs if an interpreter was present for disclosure] **Un intérprete ayudó al equipo clínico a darte a ti los resultados de las pruebas genéticas de tu hijo o hija.**

36. En general, ¿qué tan satisfecho estuviste tú con el intérprete?

- Estuve muy satisfecho
- Estuve Satisfecho
- Estuve Descontento
- Estuve muy descontento

Por favor explica por qué te sentiste de esta manera. [PRG: FREE TEXT]

37. ¿Cómo calificarías la calidad de la interpretación?

- Muy mal
- Mal
- Bueno
- Muy bien

[PRG: if select “muy mal” or “mal” above, ask:] **Por favor explica por qué te sentiste de esta manera.** [PRG: FREE TEXT]

[PRG: anything but “muy mal” or “mal” above, ask:] **¿Qué tanto sientes tú que esto impactó negativamente en tu comunicación con el equipo clínico durante la sesión?**

- Demasiada
- Suficiente
- Muy poca
- Nada

Por favor piensa tanto en el intérprete y en el/los miembro(s) del equipo clínico, como es decir el consejero genético que te dio los resultados de tu hijo o hija.

38. El intérprete y el equipo clínico trabajaron bien juntos.

- Completamente falso
- Falso
- Ni cierto ni falso
- Cierto
- Completamente cierto

Ahora, comparando el intérprete y el equipo clínico:

39. ¿Qué tan cómodo te sentiste con el intérprete y con el equipo clínico?

- Me sentí MÁS cómodo con el intérprete que con el equipo clínico.
- Me sentí MENOS cómodo con el intérprete que con el equipo clínico.
- Me sentí IGUAL de cómodo con el intérprete y con el equipo clínico.
- NO me sentí cómodo con NINGUNO, ni con el intérprete ni con el equipo clínico

40. ¿Qué tanto sentiste que el intérprete y el equipo clínico te respetaron?

- Me sentí MÁS respetado por el intérprete que por el equipo clínico
- Me sentí MENOS respetado por el intérprete que por el equipo clínico

- Me sentí IGUALMENTE respetado por AMBOS, por el intérprete y por el equipo clínico.
- NO me sentí respetado por NINGUNO, ni por el intérprete ni por el equipo clínico

41. ¿Qué tanto sientes que el intérprete y el equipo clínico comprendieron tus costumbres o creencias?

- Sentí que el intérprete comprendió mis costumbres y creencias MEJOR que como lo hicieron el equipo clínico
- Sentí que el intérprete NO comprendió mis costumbres y creencias TAN BIEN como lo hicieron el equipo clínico
- Sentí que AMBOS, el intérprete y el equipo clínico comprendieron, mis costumbres y creencias igualmente bien
- Sentí que NINGUNO, ni el intérprete ni el equipo clínico, comprendieron mis costumbres y creencias bien

42. ¿Qué tanto sentiste que tenías una conexión personal con el intérprete o con el equipo clínico?

- Sentí que tenía una conexión MÁS personal con el intérprete que con el equipo clínico.
- Sentí que tenía una conexión MENOS personal con el intérprete que con el equipo clínico.
- Sentí que tenía una conexión personal con el intérprete y con el equipo clínico.
- Sentí que NO tenía una conexión personal con NINGUNO, ni con el intérprete ni con el equipo clínico.

¡Gracias por participar en el estudio de KidsCanSeq y completar esta encuesta!

Appendix K: Parent 6 Month Follow-Up Survey (English)

Thank you for participating in the **KidsCanSeq Study** and for taking time to complete this survey. The purpose of this survey is to understand what parents of children with cancer think about genetic testing. We will also ask you how you feel about learning your child's genetic information and what you have done with the results since you received them.

Your answers to each question are important to us, but you can skip any questions that you do not want to answer. Your answers to these questions have no effect on your child's clinical care.

This survey should take about **20 minutes** to complete.

If you have questions about this study, you can call Robin Raesz-Martinez at (832)-824-7822. If you want to talk to someone who is not a part of this study or if you have concerns or complaints, you can call the Baylor College of Medicine IRB at (713)-798-6970.

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

As a reminder, you received your child's genetic tests results about six months ago on [PRG: date of disclosure or date letter mailed] [PRG: as indicated in database how results are sent to family: **in-person** OR **over the phone** OR **over videoconference** OR **by email and/or mail**]**.**

1. **How well do you understand your child's test results?**
   - ○ Not at all
   - ○ A little
   - ○ Somewhat
   - ○ Well
   - ○ Very Well

We would like to know about your experience with your child's genetic testing. We're interested in your perspective and there are no right or wrong answers.

The genetic testing my child received:

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not Applicable
2. Helped us make decisions for cancer that has come back.	○	○	○	○	○	○
3. Identified a cause for my child's cancer.	○	○	○	○	○	○
4. Correctly identified my child's chance of developing disease(s) <u>other</u> than the cancer that s/he has now.	○	○	○	○	○	○
5. May change what treatment my child receives for medical problems in the future that are not related to cancer.	○	○	○	○	○	○
6. May change what non-cancer medications my child takes.	○	○	○	○	○	○
7. May influence my child's future	○	○	○	○	○	○

decisions to have children or not.						
8. May lead me to get genetic testing or cancer screening.	○	○	○	○	○	○
9. May lead my family members to get genetic testing or cancer screening.	○	○	○	○	○	○
10. Gave me information that I want.	○	○	○	○	○	○
11. Gave me peace of mind.	○	○	○	○	○	○
12. May help me plan better for the future.	○	○	○	○	○	○
13. May influence my reproductive decisions.	○	○	○	○	○	○

Please tell us what you think about these statements.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
14. I feel comfortable letting researchers use my child's genetic information as long as they don't use his/her name.	○	○	○	○	○
15. My child's oncologist knows enough to help me understand my child's genetic information.	○	○	○	○	○
16. I trust doctors who do medical research.	○	○	○	○	○
17. It has been hard for me to cope with my child's genetic information.	○	○	○	○	○
18. I was worried that I passed genes onto my child that played a role in him/her getting cancer.	○	○	○	○	○
19. [PRG: if agree or strongly agree in Q18:] Genetic testing relieved any guilt I may have felt about potentially passing genes on to my child.	○	○	○	○	○
20. [PRG: if agree or strongly agree in Q18:] Genetic testing made any guilt I may have felt about potentially passing genes on to my child worse.	○	○	○	○	○
21. I was worried that something that I did or did not do played a role in my child getting cancer (other than passing on a gene).	○	○	○	○	○
22. [PRG: if agree or strongly agree in Q21:] Genetic testing relieved any worry that something that I did or did not do played a role in my child getting cancer (other than passing on a gene).	○	○	○	○	○
23. [PRG: if agree or strongly agree in Q21:] Genetic testing made any worry that something that I did or did not do played a role in my child getting cancer (other than passing on a gene) worse.	○	○	○	○	○
24. I'm worried about the privacy of my child's genetic information.	○	○	○	○	○

25. I'm worried that my child will not be able to get insurance because of his/her genetic information. [PRG: if agree or strongly agree ask:] Which kinds of insurance are you worried about? Check all that apply: ☐ Health insurance ☐ Life insurance ☐ Disability insurance ☐ Long term care insurance	○	○	○	○	○
26. I'm worried that my child will be treated in unfair ways because of his/her genetic information. [PRG: if agree or strongly agree:] Which kinds of unfair treatment are you worried about? Check all that apply: ☐ Job-related ☐ Financial (for example, not being able to get a loan from a bank) ☐ Social ☐ Other, please explain: [PRG: FREE TEXT]	○	○	○	○	○
27. Health insurance should pay for genetic testing for children with cancer.	○	○	○	○	○

28. On a scale of 1 to 5, how beneficial do you think genetic testing is for children with cancer?

Not at all Beneficial (1)	2	3	4	Extremely Beneficial (5)
○	○	○	○	○

[PRG: If answer 2 through 5 ask:] **Please tell us what you think the benefits of genetic testing are for children with cancer:** [PRG: FREE TEXT]

29. On a scale of 1 to 5, how risky do you think genetic testing is for children with cancer?

Not at all Risky (1)	2	3	4	Extremely Risky (5)
○	○	○	○	○

[PRG: If answer 2 through 5 ask:] **Please tell us what you think the risks of genetic testing are for children with cancer:** [PRG: FREE TEXT]

30. Please choose the description that is closest to what you think about genetic testing for children with cancer.

There are more benefits than risks.	There are an equal amount of benefits and risks.	There are more risks than benefits.
○	○	○

[PRG: Q31-35 ONLY if patient received positive diagnostic or secondary germline findings]

31. Which of the following sources, if any, did you use to find more information about the genetic test results you received? Please rate the usefulness of the sources you used. [PRG: Do not allow option responses 1-5 to be selected unless the checkbox for that row is selected. For "None", unselect all other checkboxes.]

	Not useful at all (1)	2	3	4	Very useful (5)
☐ Family or friends	○	○	○	○	○
☐ Facebook	○	○	○	○	○
☐ Support groups	○	○	○	○	○
☐ My/my child's other doctors	○	○	○	○	○
☐ Internet Search, i.e. Google, Pub Med, etc.	○	○	○	○	○
☐ Books and other print media	○	○	○	○	○
☐ Information provided by the doctor who ordered my/ my child's genetic test	○	○	○	○	○
☐ Other (please describe) [PRG: FREE TEXT BOX]	○	○	○	○	○
☐ None					

[PRG: show if "internet search" selected above] **If you used the internet to search for information about the results, please list any web sites you found helpful.** [PRG: FREE TEXT]

Please rate your level of agreement or disagreement with the following statements.

	Strongly Disagree (1)	2	3	4	5	Strongly Agree (6)
32. I understand how I and/or my child came to have this gene change.	○	○	○	○	○	○
33. I understand the health risks my relatives face because of this gene change.	○	○	○	○	○	○

34. I understand the chances I have of passing this gene change on to my children.	○	○	○	○	○	○
35. I feel that I can explain to other people what having this gene change means.	○	○	○	○	○	○

36. Since receiving your child's study results, have you shared the information with any biological family members (blood relatives)?

- ○ Yes
- ○ I didn't share this information with anyone [PRG: if selected, skip to Q48]
- ○ I haven't shared this information yet, but plan to in the future [PRG: if selected, skip to Q38]
- ○ I don't have blood relatives to share this information with [PRG: if selected, skip to Q58]

37. Since receiving your child's study results, have you shared the information with any of the following blood relatives?

	Yes	No	Not Applicable
My child's other biologic parent	○	○	○
My child(ren)	○	○	○
My siblings	○	○	○
My parents	○	○	○
My other biological family members [If select "Yes":] Please describe who: [PRG: FREE TEXT]	○	○	○

On a scale of 1 to 5, how important are each of the following reasons for sharing your child's genetic test results with blood relatives?

	Not at all important (1)	2	3	4	Very Important (5)	Not Applicable
38. To give my blood relatives information about their genetic risk	○	○	○	○	○	○
39. To encourage my blood relatives to have genetic testing	○	○	○	○	○	○
40. The doctor/genetic counselor encouraged me to share the information with blood relatives	○	○	○	○	○	○
41. So my relatives could make family planning decisions	○	○	○	○	○	○
42. To share the information I learned because I thought it was interesting	○	○	○	○	○	○

43. To share my feelings about my child's genetic test results	○	○	○	○	○	○
44. So I could get help from blood relatives with coordinating and planning for things like appointments and other health-related responsibilities (for example, going to doctors' appointments, getting child care, getting transportation, etc.)	○	○	○	○	○	○

45. Are there any other reasons why you would share the results with blood relatives? [PRG: FREE TEXT]

[PRG: If Q36 response selected is "I haven't shared, but I plan to" SKIP to Q58]

46. What type of information did you share with blood relatives? Please check all that apply.

- ☐ General information about my child's study results
- ☐ Detailed information about the genes they tested
- ☐ My relative's risk of having a condition
- ☐ Information about the possibility of being treated unfairly based on the study results
- ☐ Recommendations of ways to prevent illness
- ☐ Recommendations for more screening and testing
- ☐ Feelings about my child's study results
- ☐ Other, please specify: [PRG: FREE TEXT]

47. How did you share information about your child's genetic test results with your blood relatives? Please check all that apply.

- ☐ In person
- ☐ By phone
- ☐ By letter
- ☐ By email
- ☐ Through social media
- ☐ Other, please specify: [PRG: FREE TEXT]

On a scale of 1 to 5, how important were each of the following reasons for NOT sharing your child's genetic test results with blood relatives?

	Not at all important (1)	**2**	**3**	**4**	**Very Important (5)**	**Not Applicable**
48. I don't want to worry or upset them	○	○	○	○	○	○

49. I would have to talk to a blood relative I'm not close to/prefer not to talk to	○	○	○	○	○	○
50. I don't have contact information for my blood relatives	○	○	○	○	○	○
51. I have privacy concerns about sharing this information with my blood relatives	○	○	○	○	○	○
52. I don't know how to explain the genetic results to my relatives	○	○	○	○	○	○
53. I don't think this information is useful for my relatives	○	○	○	○	○	○
54. I'm having trouble coping with my child's results	○	○	○	○	○	○
55. I'm overwhelmed with my child's health	○	○	○	○	○	○
56. I'm worried that my relatives will treat my child differently	○	○	○	○	○	○

57. Are there any other reasons why you would NOT share the results with blood relatives? [PRG: FREE TEXT]

[PRG: For patients with a positive finding (defined as Yes to receiving diagnostic, secondary, or carrier findings):]
You will now be asked about what you did after you received your child's genetic test results, including whether you shared the results with other health care providers.

[PRG: For patients with a negative finding (defined as receiving No diagnostic, secondary, and carrier findings; may have received VUS):]
There were no changes known to cause health conditions that were found in your child's genetic test results. However, we would still like to know whether you talked to doctors or other healthcare providers about your child's test results and anything you did after you received their results.

58. Did you discuss your child's genetic test results with your child's doctors or health care providers?
- ○ Yes
- ○ Not yet, but I plan to
- ○ No, and I don't plan to

59. [PRG: If "No and I don't plan to" to Q58] **Why not? [**PRG: FREE TEXT**]**

60. [PRG: If "Yes" to Q58] **Please tell us which doctors or health care providers you have shared the results with**.
- ○ Primary care provider/ pediatrician
- ○ Oncologist
- ○ Cardiologist
- ○ Neurologist

- Other specialist(s): [PRG: FREE TEXT]

61. [PRG: If "Yes" to Q58] Did the doctor or health care provider make any recommendations to change your child's current care based on the test result?
- Yes
- No
- I don't know/ don't remember

62. [PRG: If "Yes" to Q61] **What were the recommendations that your child's doctors or healthcare providers gave you related to your child's care?**

☐ Medication *(Please check all that apply)* [PRG: If selected:]
- ☐ Start
- ☐ Stop
- ☐ Change (for example: stop taking one medication and start another one or increase or decrease the dose or frequency)

☐ Additional non-genetic medical tests for screening, monitoring, or diagnosis (*e.g.,* blood test, imaging such as x-ray, MRI, etc) *(Please check all that apply)* [PRG: If selected]:
- ☐ Start
- ☐ Stop
- ☐ Change (for example: increase or decrease the frequency)

☐ Referrals to other doctors or specialists [PRG: If selected]
- Yes (Please describe: [PRG: FREE TEXT])
- No
- Stop seeing other doctors or specialists (Please describe: [PRG: FREE TEXT])

☐ Referral to another kind of health professional who is not a medical doctor [PRG: If selected]
- ☐ New consultation with one or more of the following *(Please check all that apply):* [PRG: If selected]
  - ☐ Audiology
  - ☐ Dental
  - ☐ Genetic counselor
  - ☐ Psychologist
  - ☐ Other (Please describe: [PRG: FREE TEXT]

☐ Stop seeing another kind of health professional who is not a medical doctor

☐ Referral for mental health support *(Please check all that apply)* [PRG: If selected]
- ☐ Mental health
- ☐ Social support
- ☐ Palliative care

☐ Referral for therapy services (for example, speech, occupational, or physical) *(Please check all that apply)* [PRG: If selected]
- ☐ Speech therapy
- ☐ Occupational therapy
- ☐ Physical therapy
- ☐ Other (Please describe: [PRG: FREE TEXT]

- ☐ Lifestyle changes *(Please check all that apply)* [PRG: If selected]
  - ☐ Change diet
  - ☐ Change exercise
  - ☐ Start taking vitamins and supplements
  - ☐ Change alcohol consumption
  - ☐ Stop smoking
  - ☐ Other (Please describe: [PRG: FREE TEXT])
- ☐ Other (Please describe: [PRG: FREE TEXT])

63. [PRG: If "yes" to Q61] Have you followed the recommendations that your child's doctors or healthcare providers gave you related to your child's care?

- ○ Yes
- ○ Not yet, but I plan to
- ○ No, and I do not plan to

[PRG: If "yes"] **Which recommendations did you follow?**

- ☐ Medication [PRG: If selected:] Please describe which medication(s): [PRG: FREE TEXT]
- ☐ Medical [PRG: If selected:]
  - ☐ New consultation with a medical specialist
    [PRG: if selected:] Please describe which specialty(ies): [PRG: FREE TEXT]
  - ☐ New consultation with another kind of health professional who is not a medical doctor
    [PRG: if selected:] Please describe which health professional(s): [PRG: FREE TEXT]
  - ☐ New consultation for therapy service
    [PRG: if selected:] Please describe which therapy service(s): [PRG: FREE TEXT]
  - ☐ Any additional laboratory testing
    [PRG: if selected:] Please describe which type of lab test(s): [PRG: FREE TEXT]
  - ☐ An imaging test (such as x-ray, MRI, etc.)
    [PRG: if selected:] Please describe which type of imaging test(s): [PRG: FREE TEXT]
    [PRG: if selected:] What is the frequency?
    - ○ One time only
    - ○ Recurring
- ☐ Lifestyle
- ☐ Other (Please describe: [PRG: FREE TEXT])

64. Since receiving your child's test results, have you received counseling from your OB/GYN, reproductive genetic counselor, or primary care provider to discuss how your child's test results might affect future pregnancies?

- ○ Yes

- Not yet, but I plan to
- No, and I don't plan to
- Does not apply

[PRG: If "No and I do not plan to"] Why not? [PRG: FREE TEXT]

65. [PRG: For patients with a positive finding (defined as Yes to receiving diagnostic, secondary, or carrier findings)] **Based on your child's test results, was there any recommendation for genetic testing or other care for you, the child's other biological parent, and/or your other child(ren)?**
- Yes
- No

66. [PRG: If "Yes" to above] **Have you/your family member(s) followed up on the recommendations?**
- Yes
- Not yet, but I/we plan to
- No, and I/we do not plan to

[PRG: If "Yes" to above] **Which family member(s) followed up on the recommendations?** [PRG: FREE TEXT]

[PRG: If "Not yet" to above] **Please describe why you/your family member(s) have not yet followed up on the recommendations.** [PRG: FREE TEXT]

[PRG: If "No" to above] **Please describe why you/your family member(s) have decided not to follow up on the recommendations.** [PRG: FREE TEXT]

The last few questions ask about how decisions about your child's cancer care in general are made.

67. Which of one these best describes how you make decisions about your child's cancer care with your <u>child's doctor</u>?

- ○ I prefer to make the final selection about which treatment my child will receive.
- ○ I prefer to make the final selection of my child's treatment after seriously considering my child's doctor's opinion.
- ○ I prefer that my child's doctor and I share responsibility for deciding which treatment is best for my child.
- ○ I prefer that my child's doctor makes the final decision about which treatment will be used after seriously considering my opinion.
- ○ I prefer to leave all decisions regarding my child's treatment to my child's doctor

68. Which of one these best describes how your child is involved in decisions about their cancer care?

- ○ I prefer to make the final selection about which treatment my child will receive.
- ○ I prefer to make the final selection of my child's treatment after seriously considering my child's opinion.
- ○ I prefer that my child and I share responsibility for deciding which treatment is best for my child.

- ○ I prefer that my child makes the final decision about which treatment will be used after seriously considering my opinion.
- ○ I prefer to leave all decisions regarding my child's treatment to my child.

69. In making decisions about my child's cancer care, it is important to me that…

	Not at all Important	**Not Very Important**	**Important**	**Very Important**
My thoughts are taken into account just as much as my child's doctor's	○	○	○	○
There is enough time for questions	○	○	○	○
My child's doctor and I discuss the different treatment options thoroughly	○	○	○	○
I am able to discuss the different treatment options with my child's doctor in detail	○	○	○	○
My child's doctor and I select a treatment option together	○	○	○	○
I know the benefits of the individual treatment options	○	○	○	○
I know which treatment option is the best	○	○	○	○
I feel included in the treatment decision	○	○	○	○
I feel jointly responsible for my child's treatment	○	○	○	○

Thank you for participating in the KidsCanSeq Study and completing this survey!

Appendix L: Parent 6 Month Follow-Up Survey (Spanish)

Gracias por participar en el **Estudio KidsCanSeq** y por tomarse el tiempo para completar esta encuesta. El propósito de esta encuesta es entender qué es lo que piensan los padres de niños con cáncer sobre las pruebas genéticas. También le preguntaremos cómo se siente al conocer la información genética de su hijo(a) y qué ha hecho con los resultados desde que los recibió.

Sus respuestas a cada pregunta son importantes para nosotros, pero puede saltarse cualquier pregunta que no desee responder. Sus respuestas a estas preguntas no tienen ningún efecto en el cuidado clínico de su hijo(a).

Esta encuesta le tomará aproximadamente **20 minutos** para completarla.

Si tiene alguna pregunta sobre este estudio, puede comunicarse con Robin Raesz-Martinez al (832) 824-7822. Si desea hablar con alguien que no esté involucrado con este estudio o si tiene preocupaciones o quejas, puede llamar a la IRB de Baylor College of Medicine al (713) 798-6970.

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

Usaremos "tú" en esta encuesta para referirnos a usted, el padre o la madre del paciente.

Como recordatorio, recibiste los resultados de la prueba genética de tu hijo(a) hace aproximadamente 6 meses el [PRG part 1: show date of disclosure or date letter mailed: MM/DD/YYYY] [PRG part 2: show which method results were received; if in person: "**en persona"** OR if over the phone "**por teléfono"** OR if over telemedicine/video: "**por videoconferencia"** OR if by letter in the mail or email: "**por email/correo electrónico o por correo"**]**.**

1. ¿Qué tan bien entiendes los resultados de las pruebas de tu hijo(a)?

- Nada
- Un poco
- Regular
- Bastante
- Extremadamente

Nos gustaría conocer tu experiencia con las pruebas genéticas de tu hijo(a). Estamos interesados en tu perspectiva y no hay respuestas correctas o incorrectas.

Las pruebas genéticas que mi hijo(a) recibió:

	Definitivamente no estoy de acuerdo	**No estoy de acuerdo**	**Neutral**	**Estoy de acuerdo**	**Definitivamente estoy de acuerdo**	**No Aplica**
2. Nos ayudaron a tomar decisiones relacionados al cáncer que ha vuelto.	○	○	○	○	○	○
3. Identificaron una causa del cáncer de mi hijo(a).	○	○	○	○	○	○
4. Identificaron si mi hijo(a) puede desarrollar otra(s) enfermedad(es) además del cáncer que él/ella tiene ahora.	○	○	○	○	○	○
5. Pueden cambiar el tratamiento que mi hijo(a) recibirá en el futuro por si acaso tiene problemas médicos que no estén relacionados con el cáncer.	○	○	○	○	○	○

6. Pueden cambiar los medicamentos que toma mi hijo(a) que no sean para el cáncer.	○	○	○	○	○	○
7. Pueden influir en la decisión de mi hijo(a) de tener hijos o no en el futuro.	○	○	○	○	○	○
8. Mandar hacerme pruebas genéticas o pruebas de cáncer.	○	○	○	○	○	○
9. Pueden llevar a los miembros de mi familia a hacerse pruebas genéticas o de cáncer.	○	○	○	○	○	○
10. Me dieron información que yo deseo.	○	○	○	○	○	○
11. Me dieron tranquilidad.	○	○	○	○	○	○
12. Pueden dejarme planear mejor el futuro.	○	○	○	○	○	○
13. Pueden influir en mis decisiones reproductivas.	○	○	○	○	○	○

Por favor dinos qué piensas sobre estas declaraciones.

	Definitivamente no estoy de acuerdo	**No estoy de acuerdo**	**Neutral**	**Estoy de acuerdo**	**Definitivamente estoy de acuerdo**
14. Me siento cómodo/a permitiendo que los investigadores utilicen la información genética de mi hijo(a) siempre y cuando no utilicen su nombre.	○	○	○	○	○
15. El oncólogo de mi hijo(a) sabe lo suficiente para ayudarme a comprender la información genética de mi hijo(a).	○	○	○	○	○
16. Confío en los médicos que realizan estudios de investigación clínica.	○	○	○	○	○

17. Ha sido duro para mí lidiar con la información genética de mi hijo(a).	○	○	○	○	○
18. Estaba preocupado/a de haberle pasado genes a mi hijo(a) que hayan jugado un papel en el que él/ella se haya enfermado de cáncer.	○	○	○	○	○
19. [PRG: if “Estoy de acuerdo” or “Definitivamente estoy de acuerdo” in Q18:] Las pruebas genéticas me liberaron de cualquier culpa que hubiera podido sentir sobre la posibilidad de haberle pasado genes a mi hijo(a).	○	○	○	○	○
20. [PRG: if “Estoy de acuerdo” or “Definitivamente estoy de acuerdo” in Q18:] Las pruebas genéticas agravaron cualquier culpa que hubiera podido sentir sobre la posibilidad de haberle pasado genes a mi hijo(a).	○	○	○	○	○
21. Estaba preocupado/a de que algo que hubiera hecho o que no hubiera hecho jugara un papel en el que mi hijo(a) se haya enfermado de cáncer (además de pasarle un gen).	○	○	○	○	○
22. [PRG: if “Estoy de acuerdo” or “Definitivamente estoy de acuerdo” in Q21:] Las pruebas genéticas me liberaron de cualquier preocupación de que algo que hubiera hecho o que no hubiera hecho jugara un papel en el que mi hijo(a) se haya enfermado de cáncer (además de pasarle un gen).	○	○	○	○	○
23. [PRG: if “Estoy de acuerdo” or “Definitivamente estoy de acuerdo” in Q21:] Las pruebas genéticas agravaron cualquier preocupación de que algo que hubiera hecho o que no hubiera hecho jugara un papel en el que mi hijo(a) se haya enfermado de cáncer (además de pasarle un gen).	○	○	○	○	○
24. Estoy preocupado/a por la privacidad de la información genética de mi hijo(a).	○	○	○	○	○

25. Estoy preocupado/a de que mi hijo(a) no pueda obtener un seguro debido a los resultados de las pruebas genéticas. [PRG: if “Estoy de acuerdo” or “Definitivamente estoy de acuerdo” ask:] ¿Por qué tipos de seguro estás preocupado/a? Por favor, marca todos los que correspondan: ☐ Seguro de salud ☐ Seguro de vida ☐ Seguro por discapacidad ☐ Seguro de cuidados a largo plazo	○	○	○	○	○
26. Estoy preocupado/a de que mi hijo(a) sea tratado injustamente por su información genética. [PRG: if “Estoy de acuerdo” or “Definitivamente estoy de acuerdo”:] ¿Qué tipo de tratamiento injusto te preocupa? Por favor, marca todos los que correspondan: ☐ Relacionado con el trabajo ☐ Financiero (por ejemplo, no poder obtener un préstamo bancario) ☐ Social ☐ Otros, por favor explica: [PRG: FREE TEXT]	○	○	○	○	○
27. El seguro de salud debería pagar las pruebas genéticas para niños con cáncer.	○	○	○	○	○

28. En una escala del 1 al 5, ¿qué tan beneficiosas crees que son las pruebas genéticas para niños con cáncer?

Nada beneficiosas (1)	**2**	**3**	**4**	**Extremadamente beneficiosas (5)**
○	○	○	○	○

[PRG: If answer 2 through 5 ask:] **Por favor dinos cuáles crees que sean los beneficios de las pruebas genéticas para niños con cáncer:** [PRG: FREE TEXT]

29. En una escala del 1 al 5, ¿qué tan riesgosas crees que son las pruebas genéticas para niños con cáncer?

Nada riesgosas (1)	2	3	4	Extremadamente riesgosas (5)
○	○	○	○	○

[PRG: If answer 2 through 5 ask:] **Por favor dinos cuáles crees que sean los riesgos de las pruebas genéticas para niños con cáncer:** [PRG: FREE TEXT]

30. Por favor elije la descripción que más se acerque a lo que piensas sobre las pruebas genéticas para niños con cáncer.

Hay más beneficios que riesgos.	Hay la misma cantidad de beneficios y de riesgos.	Hay más riesgos que beneficios.
○	○	○

[PRG: Q31-35 ONLY if patient received positive diagnostic or secondary germline findings]

31. ¿Cuál de las siguientes fuentes, si alguna, utilizaste para obtener más información sobre los resultados de las pruebas genéticas que recibiste? Por favor, califica la utilidad de las fuentes que utilizaste.
[PRG: Do not allow option responses 1-5 to be selected unless the checkbox for that row is selected. For "Nada", unselect all other checkboxes.]

	No fue útil para nada (1)	2	3	4	Muy útil (5)
☐ Familia o amigos	○	○	○	○	○
☐ Facebook	○	○	○	○	○
☐ Grupos de apoyo	○	○	○	○	○
☐ Mis otros doctores o los doctores de mi hijo(a)	○	○	○	○	○
☐ Busqué en Internet, i.e. Google, Pub Med, etc.	○	○	○	○	○
☐ Libros y publicaciones	○	○	○	○	○
☐ Información que me dio el doctor que ordenó la prueba de mi hijo(a)	○	○	○	○	○
☐ Otra cosa (por favor especifica) [PRG: FREE TEXT BOX]	○	○	○	○	○
☐ Nada					

[PRG: show if "internet search" selected above] **Si usaste Internet para buscar información sobre los resultados, por favor anota qué sitios de Internet te resultaron útiles.** [PRG: FREE TEXT]

Por favor marca qué tan cierto es para ti lo que dice cada una de las siguientes frases.

	Completamente falso (1)	2	3	4	5	Completamente cierto (6)
32. Entiendo cómo es que yo y/o mi hijo(a) tenemos este cambio genético.	○	○	○	○	○	○
33. Entiendo cuáles son los riesgos de salud que tienen mis parientes debido a este cambio genético.	○	○	○	○	○	○
34. Entiendo las probabilidades o chances que hay de que yo les pase este cambio genético a mis hijos.	○	○	○	○	○	○
35. Creo que puedo explicarles a otras personas lo que significa tener este cambio genético.	○	○	○	○	○	○

36. Desde que recibiste los resultados de tu hijo(a), ¿has compartido esa información con alguna persona de tu familia directa (es decir, un pariente biológico directo)?

- ○ Sí
- ○ No compartí esta información con nadie [PRG: if selected, skip to Q48]
- ○ Todavía no he compartido esta información, pero pienso hacerlo en el futuro [PRG: if selected, skip to Q38]
- ○ No tengo parientes directos con quienes compartir esta información [PRG: if selected, skip to Q58]

37. Desde que recibiste tus resultados o los resultados de tu hijo(a), ¿has compartido la información con alguno de los siguientes parientes directos?

	Sí	No	No Aplica
El otro padre biológico de mi hijo(a)	○	○	○
Mi hijo(a) (o hijos/hijas)	○	○	○
Mis hermanos/hermanas	○	○	○
Mis padres	○	○	○
Mis otros parientes biológicos directos [If select "Yes":] Por favor especifica con quién: [PRG: FREE TEXT]	○	○	○

Usando una escala del 1 al 5, ¿qué tan importante es cada una de las siguientes razones para que compartieras los resultados de las pruebas de tu hijo(a) con tus parientes biológicos directos?

	Nada importante (1)	2	3	4	Muy Importante (5)	No Aplica

38. Para darles a mis parientes directos información sobre su riesgo genético	○	○	○	○	○	○
39. Para animar a que mis parientes directos se hagan pruebas genéticas	○	○	○	○	○	○
40. El doctor o consejero genético me animó a que compartiera la información con mis parientes biológicos	○	○	○	○	○	○
41. Para que mis parientes pudieran tomar decisiones de planificación familiar	○	○	○	○	○	○
42. Compartí la información que me dieron porque me pareció interesante	○	○	○	○	○	○
43. Para compartir lo que siento sobre los resultados de las pruebas genéticas de mi hijo(a)	○	○	○	○	○	○
44. Para que mis parientes biológicos pudieran ayudarme a coordinar y planear cosas como citas médicas y otras responsabilidades relacionadas con mi salud (por ejemplo, ir a citas médicas conmigo, cuidar a mis hijos, o a llevarme a alguna cita, etc.)	○	○	○	○	○	○

45. ¿Hay algunas otras razones por las que compartirías los resultados con tus parientes biológicos? [PRG: FREE TEXT]

[PRG: If Q36 response selected is “I haven’t shared, but I plan to” SKIP to Q48]

46. ¿Qué tipo de información compartiste con tus parientes biológicos? Por favor marca todas las respuestas que apliquen.

- ☐ Información general sobre los resultados del estudio
- ☐ Información detallada sobre los genes que analizaron
- ☐ El riesgo de mi pariente de tener una condición médica
- ☐ Información sobre la posibilidad de ser tratado injustamente en base a los resultados del estudio
- ☐ Recomendaciones sobre maneras de prevenir la enfermedad
- ☐ Recomendaciones sobre tener más pruebas o exámenes
- ☐ Cómo me sentí acerca de los resultados del estudio

☐ Otra cosa, por favor especifica: [PRG: FREE TEXT]

47. ¿De qué manera compartiste los resultados de la prueba genética de tu hijo(a) con tus parientes biológicos? Por favor marca todas las respuestas que apliquen.

☐ En persona
☐ Por teléfono
☐ Por carta
☐ Por email o correo electrónico
☐ A través de las redes sociales (como Facebook)
☐ De otra manera, por favor especifica: [PRG: FREE TEXT]

[PRG: If "Sí" to Q36, SKIP to Q58.]

Usando una escala del 1 al 5, ¿qué tan importante fue cada una de las siguientes razones para que tú NO compartieras los resultados de tu hijo(a) con tus parientes biológicos?

	Nada importante (1)	**2**	**3**	**4**	**Muy Importante (5)**	**No Aplica**
48. No quiero preocuparlos o hacerlos sentir mal	○	○	○	○	○	○
49. Tendría que hablar con un pariente biológico con quien prefiero no hablar o con quien no tengo una relación cercana	○	○	○	○	○	○
50. No tengo información para ponerme en contacto con mis parientes biológicos	○	○	○	○	○	○
51. Me preocupa que mi privacidad no se mantenga si comparto esta información con mis parientes	○	○	○	○	○	○
52. No sé cómo explicarles a mis parientes los resultados de la prueba genética	○	○	○	○	○	○
53. No creo que esta información sea útil a mis parientes	○	○	○	○	○	○
54. Me está resultando difícil hacerles frente a mis resultados/ los resultados de mi hijo(a)	○	○	○	○	○	○
55. Me siento agobiado por mi salud o por la salud de mi hijo(a)	○	○	○	○	○	○
56. Me preocupa que mis parientes no vayan a tratarme como antes a mí o a mi hijo(a)	○	○	○	○	○	○

57. **¿Hay otras razones por las que NO compartirías los resultados con parientes biológicos?** [PRG: FREE TEXT]

[PRG: For patients with a positive finding (defined as Yes to receiving diagnostic, secondary, or carrier findings):]
Ahora vamos a preguntarte sobre lo que hiciste después de que recibiste los resultados de las pruebas genéticas de tu hijo(a), incluyendo si compartiste tus resultados con otros doctores o profesionales de la salud.

[PRG: For patients with a negative finding (defined as receiving No diagnostic, secondary, and carrier findings; may have received VUS):]
No hubo cambios encontrados en los resultados de la prueba genética de su hijo/a que se sepa que causen enfermedades. De cualquier manera, queremos saber si hablaste con algún doctor o profesional de la salud sobre los resultados de tu hijo(a), y también queremos saber qué otra cosa hiciste después de recibir los resultados.

58. **¿Hablaste sobre los resultados de las pruebas genéticas de tu hijo(a) con los doctores de tu hijo(a) o con algún profesional de la salud?**
    - Sí
    - No todavía, pero pienso hacerlo
    - No, y no pienso hacerlo

59. **[**PRG: If "No, y no pienso hacerlo" to Q58] **¿Por qué no? [**PRG: FREE TEXT**]**

60. **[**PRG: If "Sí" to Q58] **Por favor indica con qué doctores o profesionales de la salud has compartido los resultados**.
    - El médico principal (médico de cabecera) o pediatra
    - Oncólogo
    - Cardiólogo
    - Neurólogo
    - Otra(s) especialista(s): [PRG: FREE TEXT]

61. [PRG: If "Sí" to Q58] **¿Recomendó algo el doctor o profesional de la salud de tu hijo(a) en base a los resultados de la prueba?**
    - Sí
    - No
    - No sé/ No recuerdo

62. [PRG: If "Sí" to Q61] **¿Cuáles fueron las recomendaciones que los médicos o proveedores de salud de tu hijo(a) te dieron en relación con el cuidado de tu hijo(a)?**
    - ☐ Medicamentos (por favor marca todas las respuestas que apliquen) [PRG: If selected:]
        - ☐ Empezar a tomarlos
        - ☐ Dejar de tomarlos
        - ☐ Cambiarlos (por ejemplo, dejar de tomar una medicina y empezar a tomar otra, o subir o bajar la dosis o la frecuencia del medicamento)
    - ☐ Otras pruebas no-genómicas para chequeo, monitoreo, o diagnóstico (por ejemplo, prueba de sangre, radiografías, escaneos por MRI, etc) (por favor marca todas las respuestas que apliquen) [PRG: If selected]:

- ☐ Empezar
- ☐ Dejar de hacerlas
- ☐ Cambiar (por ejemplo, subir o bajar la frecuencia)

☐ Referir a tu hijo(a) a consulta con otros doctores o especialistas [PRG: If selected]
- Sí (por favor especifica: [PRG: FREE TEXT])
- No
- Dejar de ver a otros doctores o especialistas (por favor especifica: [PRG: FREE TEXT])

☐ Refirieron a tu hijo(a) a un profesional de la salud no médico [PRG: If selected]

☐ Refirieron a tu hijo(a) a una nueva consulta con uno o más de los siguientes (por favor marca todas las respuestas que apliquen*):* [PRG: If selected]
- ☐ Audiología
- ☐ Dentista
- ☐ Consejero genético
- ☐ Psicólogo
- ☐ Otro (Por favor especifica): [PRG: FREE TEXT]

☐ Te dijeron que dejaras de ver a algún profesional de la salud no médico

☐ Refirieron a tu hijo(a) a buscar apoyo para la salud mental (por favor marca todas las respuestas que apliquen) [PRG: If selected]
- ☐ Salud mental
- ☐ Apoyo social
- ☐ Cuidados paliativos

☐ Refirieron a tu hijo(a) a servicios terapéuticos (por ejemplo, terapia de lenguaje, ocupacional, o física) (por favor marca todas las respuestas que apliquen) [PRG: If selected]
- ☐ Terapia de lenguaje
- ☐ Terapia ocupacional
- ☐ Terapia física
- ☐ Otro (Por favor especifica): [PRG: FREE TEXT]

☐ Recomendaron que tu hijo(a) hiciera cambios en su estilo de vida (por favor marca todas las respuestas que apliquen) [PRG: If selected]
- ☐ Cambiar su dieta
- ☐ Cambiar su actividad física o ejercicio
- ☐ Empezar a tomar vitaminas y suplementos
- ☐ Cambiar su consumo de alcohol
- ☐ Dejar de fumar
- ☐ Otro (Por favor especifica): [PRG: FREE TEXT])

☐ Otro (Por favor especifica): [PRG: FREE TEXT])

63. [PRG: If “Sí” to Q61] **¿Has seguido las recomendaciones que los médicos o los proveedores de salud de tu hijo(a) te dieron en relación con el cuidado de tu hijo(a)?**
- Sí
- No todavía, pero pienso hacerlo

- No, y no pienso hacerlo

[PRG: If "Sí"] **¿Qué recomendaciones seguiste?**

- ☐ Medicamentos [PRG: If selected:] Por favor especifica qué medicamento(s): [PRG: FREE TEXT]
- ☐ Medica [PRG: If selected:]
  - ☐ Nueva consulta con un especialista médico
    [PRG: if selected:] Por favor especifica qué especialidad(es): [PRG: FREE TEXT]
  - ☐ Nueva consulta con un profesional de la salud no médico
    [PRG: if selected:] Por favor especifica qué profesional(es) de la salud no médico(s): [PRG: FREE TEXT]
  - ☐ Nueva consulta para servicio terapéutico
    [PRG: if selected:] Por favor especifica qué servicio(s) terapéutico(s): [PRG: FREE TEXT]
  - ☐ Alguna otra prueba de laboratorio [PRG: if selected:] Por favor especifica qué tipo de prueba(s) de laboratorio: [PRG: FREE TEXT]
  - ☐ Hacerte alguna(s) prueba de escaneo (como radiografías, MRI, etc.)
    [PRG: if selected:] Por favor especifica qué tipo de escaneo(s): [PRG: FREE TEXT]
    [PRG: if selected:] ¿Con qué frecuencia?
    - Sólo una vez
    - Recurrente
- ☐ Estilo de vida
- ☐ Otro (Por favor especifica): [PRG: FREE TEXT])

64. Desde que recibiste los resultados de tu hijo(a), ¿has recibido asesoría de parte de un ginecólogo/obstetra, consejero genético de reproducción, o médico general sobre cómo los resultados de tu hijo(a) podría afectar futuros embarazos?

- Sí
- Todavía no, pero pienso hacerlo
- No, y no pienso hacerlo
- No aplica

[PRG: If "No, y no pienso hacerlo"] **¿Por qué no?** [PRG: FREE TEXT]

65. [PRG: For patients with a positive finding (defined as Yes to receiving diagnostic, secondary, or carrier findings)] **Basados en los resultados de las pruebas de tu hijo(a), ¿hubo alguna recomendación para realizar pruebas genéticas u otro cuidado para ti, el otro padre biológico de tu hijo(a), y/o tus otros hijos o hijas?**

- Sí
- No

66. [PRG: If "Sí" to above] **¿Han dado tú o los miembros de tu familia un seguimiento de las recomendaciones?**

- Sí
- Todavía no, pero pienso/pensamos hacerlo
- No, y no pienso/pensamos hacerlo

[PRG: If “Sí” to above] **¿Qué miembro(s) de tu familia han dado seguimiento a las recomendaciones?** [PRG: FREE TEXT]

[PRG: If “Todavía no” to above] **Por favor describa por qué tú o los miembros de tu familia todavía no han dado aún seguimiento a las recomendaciones.** [PRG: FREE TEXT]

[PRG: If “No” to above] **Por favor describa por qué tú o los miembros de tu familia han decidido no dar seguimiento a las recomendaciones.** [PRG: FREE TEXT]

Las últimas preguntas se refieren a cómo se toman las decisiones sobre el cuidado del cáncer de tu hijo(a) en general.

67. ¿Cuál de estos describe mejor cómo tomas decisiones sobre el cuidado del cáncer de tu hijo(a) con el médico de tu hijo(a)? Marca una.

- ○ Prefiero hacer la selección final sobre el tratamiento que recibirá mi hijo(a).
- ○ Prefiero hacer la selección final del tratamiento de mi hijo(a) después de considerar seriamente la opinión del médico de mi hijo(a).
- ○ Prefiero que el médico de mi hijo(a) y yo compartamos la responsabilidad de decidir cuál tratamiento es mejor para mi hijo(a).
- ○ Prefiero que el médico de mi hijo(a) tome la decisión final sobre qué tratamiento se utilizará después de considerar seriamente mi opinión.
- ○ Prefiero dejar todas las decisiones relativas al tratamiento de mi hijo(a) al médico de mi hijo(a).

68. ¿Cuál de estos describe mejor cómo participa tu hijo(a) en las decisiones sobre su atención para el cáncer? Marca una.

- ○ Prefiero hacer la selección final sobre el tratamiento que recibirá mi hijo(a).
- ○ Prefiero hacer la selección final del tratamiento de mi hijo(a) después de considerar seriamente la opinión de mi hijo(a).
- ○ Prefiero que mi hijo(a) y yo compartamos la responsabilidad de decidir cuál tratamiento es mejor para mi hijo(a).
- ○ Prefiero que mi hijo(a) tome la decisión final sobre qué tratamiento se utilizará después de considerar seriamente mi opinión.
- ○ Prefiero dejar todas las decisiones relativas al tratamiento de mi hijo(a) en manos de mi hijo(a) a mi hijo(a).

69. Al tomar decisiones sobre el cuidado del cáncer de mi hijo(a), para mí es importante que...

	Nada Importante	No muy Importante	Importante	Muy Importante
70. Mis ideas se consideren en igual medida que las del médico de mi hijo(a)	○	○	○	○
71. Haya tiempo suficiente para hacer preguntas	○	○	○	○
72. El médico de mi hijo(a) y yo discutimos las diferentes opciones de tratamiento detalladamente.	○	○	○	○

	Nada Importante	No muy Importante	Importante	Muy Importante
73. Ser capaz de discutir las diferentes opciones de tratamiento con el médico de mi hijo(a) en detalle	○	○	○	○
74. El médico de mi hijo(a) y yo seleccionemos juntos una opción de tratamiento	○	○	○	○
75. Conocer los beneficios de las opciones de tratamiento individuales	○	○	○	○
76. Saber cuál opción de tratamiento es la mejor	○	○	○	○
77. Sentirme incluido en la decisión del tratamiento	○	○	○	○
78. Sentir una responsabilidad compartida por el tratamiento de mi hijo(a).	○	○	○	○

¡Gracias por participar en el Estudio KidsCanSeq y completar esta encuesta!

Appendix M: Adolescents and Young Adult (AYA) 6-Month Post-Disclosure Survey (English)

Thanks for being in the **KidsCanSeq** study and for taking time to do this survey. As a reminder, the KidsCanSeq study included genetic testing of your blood sample, and in some cases tumor samples, to learn genetic information that might be important for the care of childhood cancer patients and close family members.

The purpose of this survey is to understand what you and other patients with cancer who are around your age think about genetic testing, what it might be useful for, and your decision-making preferences. **In this survey when we refer to your parents, we mean your parent(s) and/or legal guardian(s).**

You can skip any questions that you don't want to answer. You can stop at any time and restart, and you can do this survey on your own computer or mobile device. Your answers to these questions have no effect on your clinical care and will be kept private.

When answering these questions, please think about the genetic testing you had as a part of the KidsCanSeq study, and not any other genetic testing you may have had before being in the study.

This survey should take about **15 minutes** to complete.

If you have questions about this study, you can call Robin Raesz-Martinez at (832) 824-7822. If you want to talk to someone who is not a part of this study or if you have concerns or complaints, you can call the Baylor College of Medicine IRB at (713) 798-6970.

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

Do you want to take this survey in English or Spanish?
¿Deseas completar esta encuesta en inglés o español?

- English/ Inglés
- Spanish/ Español

[PRG: If "English/Ingles", start "English AYA 6-Mo PD Survey". If "Spanish/Español", start "Spanish AYA 6-mo PD Survey"]

You or your parent(s) received your genetic test results about six months ago in-person, over the phone, over videoconference, or by email and/or mail.

1. **Have you seen your genetic test results or has someone talked to you about them?**
   - Yes
   - No [PRG: if No selected show check boxes:] **Why haven't you seen your results or talked to anyone about them? Please select all that apply.**
     - ☐ My family didn't receive any results
     - ☐ I haven't heard anything about my results
     - ☐ I plan to talk about my results with my parent(s) but haven't yet
     - ☐ I'm not interested in knowing my results [PRG: if selected: Why don't you want to know your genetic test results? [PRG: Free text box]
     - ☐ Other [PRG: Please explain]

[PRG: If No and "I'm not interested in knowing my results" selected, show]: "**Why don't you want to know your genetic test results?"**

2. **How did you hear about your genetic test results? Please select all that apply.**
   - ☐ I was there when the study genetic counselor met with my parent(s) to go over the test results.
   - ☐ My oncologist told me and my parent(s) about my genetic test results
   - ☐ Another doctor or nurse talked to me and my parent(s) about my results
   - ☐ I talked with my oncologist, genetic counselor, or another doctor about my genetic test results **without** my parent(s) present
   - ☐ I read the letter and/or report that was sent to my family that explained the results
   - ☐ My parent(s) told me about my genetic test results
   - ☐ Other [PRG: Free text box]

Please tell us how you felt about receiving your genetic test results.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not Applicable
3. I was treated with sensitivity and respect.	○	○	○	○	○	○
4. The clinical team checked to make sure I understood the information.	○	○	○	○	○	○
5. I felt I had the information and support available to me to answer any questions I had after receiving my genetic results.	○	○	○	○	○	○
6. I felt comfortable asking questions and voicing my concerns.	○	○	○	○	○	○

7. How well do you understand your test results?

- ○ Not applicable—I haven't seen my results and no one has talked to me about them
- ○ Not at all
- ○ A little
- ○ Somewhat
- ○ Well
- ○ Very Well

The next few questions ask about how you and your family make decisions about your cancer care in general, as well as how the decision to participate in the KidsCanSeq study was made.

8. **Which one of these best describes how <u>you would prefer</u> to make decisions about your cancer care?**
   - ○ I prefer to make the final decision about which treatment I receive
   - ○ I prefer to make the final decision about my treatment after seriously considering my parent(s)' opinion
   - ○ My parent(s) and I prefer to share responsibility for deciding which treatment is best for me
   - ○ I prefer that my parent(s) make the final decision about my treatment after seriously considering my opinion
   - ○ I prefer to leave all decisions regarding my treatment to my parent(s)

9. **Which one of these best describes how decisions about your cancer care are <u>actually</u> made?**
   - ○ I make the final decision about which treatment I receive
   - ○ I make the final decision about my treatment after seriously considering my parent (s)' opinion
   - ○ My parent(s) and I share responsibility for deciding which treatment is best for me
   - ○ My parent(s) make the final decision about my treatment after seriously considering my opinion
   - ○ I leave all decisions regarding my treatment to my parent(s)

10. Please rate how important each of these items are to you, from Not at all Important to Very Important.

    In making decisions about my cancer care, it is important to me that…

	Not at all Important	**Not Very Important**	**Important**	**Very Important**
My thoughts are taken into account just as much as my doctor's	○	○	○	○
There is enough time for questions	○	○	○	○
My doctor and I discuss the different treatment options thoroughly	○	○	○	○
I am able to discuss the different treatment options with my doctor in detail	○	○	○	○
My doctor and I select a treatment option together	○	○	○	○
I know the benefits of the individual treatment options	○	○	○	○
I know which treatment option is the best	○	○	○	○

	Not at all Important	Not Very Important	Important	Very Important
I feel included in the treatment decision	○	○	○	○
I feel jointly responsible for my treatment	○	○	○	○

The next few questions ask only about your decision to participate in the KidsCanSeq study. These questions are not about how you generally make decisions about your cancer care.

11. How was the decision made for you to participate in the KidsCanSeq Study?

- ○ I made the decision to participate
- ○ I made the decision to participate after seriously considering my parent(s)' opinion
- ○ My parent(s) and I made the decision together
- ○ My parent(s) made the decision to participate after seriously considering my opinion
- ○ My parent(s) made the decision to participate

12. How satisfied were you with the role you had in the decision to participate in the KidsCanSeq study and have genetic testing?

- ○ Very satisfied
- ○ Somewhat satisfied
- ○ Somewhat dissatisfied
- ○ Very dissatisfied

We would like to know in what ways you think genetic testing is useful. We're interested in your opinions and there are no right or wrong answers.

The genetic testing I received:

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
13. May help with making decisions if my cancer comes back.	○	○	○	○	○
14. Identified a cause for my cancer.	○	○	○	○	○
15. Identified my chance of developing disease(s) other than cancer.	○	○	○	○	○
16. May change what treatment I receive for medical problems in the future that are not related to cancer.	○	○	○	○	○

17. May change what non-cancer medications I take.	○	○	○	○	○
18. May influence my future decisions to have children or not.	○	○	○	○	○
19. May lead my family members to get genetic testing or cancer screening.	○	○	○	○	○
20. Gave me information that I want.	○	○	○	○	○
21. Gave me peace of mind.	○	○	○	○	○
22. May help me plan better for the future.	○	○	○	○	○

How much do you agree with the following statements?

	Strongly Disagree	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
23. I feel comfortable letting researchers use my genetic information if they don't use my name.	○	○	○	○	○
24. My oncologist knows enough to help me understand my genetic information.	○	○	○	○	○
25. I trust doctors who do medical research.	○	○	○	○	○
26. I trust my oncologist/my oncology team	○	○	○	○	○
27. It has been hard for me to cope with my genetic information.	○	○	○	○	○
28. I'm worried about the privacy of my genetic information.	○	○	○	○	○
29. I'm worried that I will be treated in unfair ways because of my genetic information. [PRG: if agree or strongly agree:] Which kinds of unfair treatment are you worried about? Check all that apply: ☐ Job-related	○	○	○	○	○

☐ Financial (for example, not being able to get a loan from a bank) ☐ Social ☐ Other, please explain: [PRG: FREE TEXT]					

30. In the last 12 months, have you and your parent and/or oncologist talked about you being more in charge of decisions related to your health?

- ○ No
- ○ Yes [PRG Checkbox if Yes selected: **Who have you talked to?**
  - ○ My parent(s)
  - ○ My oncologist(s)
  - ○ Both my parent(s) and my oncologist(s)

31. How well do you speak English?

- ○ Native English-speaker
- ○ Very well
- ○ Well
- ○ Not well

32. What language do you prefer to speak with <u>your doctors</u>?

- ○ English
- ○ Another language
- ○ I am equally comfortable discussing my medical care with <u>my doctors</u> in BOTH English and another language

[PRG: If "another language" selected in above Q:] **Please tell us which language you prefer to speak with your doctors:** [PRG: Spanish, Vietnamese, Chinese (Mandarin, Cantonese, or other Chinese language), Tagalog, German, French, Korean, Russian, Arabic, Other (please describe): [PRG: FREE TEXT]

33. What language do you prefer to speak with <u>your parents</u> about your medical information?

- ○ English
- ○ Another language
- ○ I am equally comfortable discussing my medical information with <u>my parent(s)</u> in BOTH English and another language

[PRG: If "another language" selected in above Q:] **Please tell us which language you prefer to speak with your parent(s) about your medical information:** [PRG: Spanish, Vietnamese, Chinese (Mandarin, Cantonese, or other Chinese language), Tagalog, German, French, Korean, Russian, Arabic, Other (please describe): [PRG: FREE TEXT]

34. Have you ever had to translate medical information for your parent(s) in a clinical setting?

- ○ Yes
- ○ No [PRG: END SURVEY with SUBMIT instructions and THANK YOU]

[PRG: If "Yes" selected in above Q:] **How often have you had to translate medical information for your parent(s) in a clinical setting?**

- ○ Always
- ○ Often
- ○ Sometimes
- ○ Occasionally
- ○ Never

[PRG: If "Yes" selected in above Q:] **How comfortable do you feel translating medical information for your parent(s) in clinical settings?**

- ○ Very comfortable
- ○ Somewhat comfortable
- ○ Somewhat uncomfortable
- ○ Very uncomfortable

We would like to send you a $25 gift card as a thank you for completing this survey

If you would like a $25 gift card, please enter your FULL NAME and EMAIL ADDRESS below so we can send it to you electronically. Your responses will be kept confidential. It may take up to one week for you to receive your card.

PLEASE NOTE: We can only send your gift card if you provide your name and email address.

If you have any questions about your gift card, do not receive your gift card, or have trouble activating or using your gift card, please contact Jill Robinson at jill.robinson@bcm.edu or (713) 798-5848.

First name: FREE TEXT
Last name: FREE TEXT
Email address: FREE TEXT
Please enter your Email Address again to confirm: FREE TEXT

Thank you for participating in the KidsCanSeq Study and taking this survey!

Appendix N: Adolescents and Young Adult (AYA) 6-Month Post-Disclosure Survey (Spanish)

Gracias por participar en el **estudio KidsCanSeq** y por darte el tiempo de responder esta encuesta. Como recordatorio, el estudio KidsCanSeq incluyó un examen genético de tu muestra de sangre, y en algunos casos de muestras de tumores, a fin de adquirir información genética que podría ser de importancia para el cuidado de pacientes de cáncer infantil y miembros de la familia cercana.

El propósito de esta encuesta es comprender qué piensas tú y otros pacientes con cáncer que tienen aproximadamente tu edad sobre las pruebas genéticas, para qué podrían ser útiles, y tus preferencias a la hora de tomar decisiones. **En esta encuesta, cuando mencionamos a tu padre(s), nos referimos a tu padre(s) y/o tutor(es) legal.**

Puedes omitir cualquier pregunta que no quieras responder. Puedes detenerte en cualquier momento y reanudarla luego, y puedes contestar esta encuesta en tu propia computadora o dispositivo móvil. Tus respuestas a estas preguntas no tienen ningún efecto en tu atención clínica y se mantendrán privadas.

Cuando respondas estas preguntas, por favor piensa en las pruebas genéticas que recibiste como parte del estudio KidsCanSeq, y no en algún otro examen genético que te hayas hecho antes del estudio.

Esta encuesta te tomará aproximadamente **15 minutos** para completarla.

Si tiene alguna pregunta sobre este estudio, puede comunicarse con Robin Raesz-Martinez al (832) 824-7822. Si desea hablar con alguien que no esté involucrado con este estudio o si tiene preocupaciones o quejas, puede llamar a la IRB de Baylor College of Medicine al (713) 798-6970.

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

Do you want to take this survey in English or Spanish?
¿Deseas completar esta encuesta en inglés o español?

- English/ Inglés
- Spanish/ Español

[PRG: If "English/Ingles", start "English AYA 6-Mo PD Survey". If "Spanish/Español", start "Spanish AYA 6-mo PD Survey"]

Tú o tu padre(s) recibió los resultados de tus pruebas genéticas hace aproximadamente 6 meses en persona, por teléfono, por videoconferencia, o por email/correo electrónico o por correo.

1. **¿Has visto los resultados de tus pruebas genéticas o alguien te ha hablado sobre ellos?**
   - Sí
   - No [PRG: if No selected, show checkboxes:] **¿Por qué no has visto tus resultados o has hablado con alguien sobre ellos? Por favor selecciona todas las que correspondan:**
     - ☐ Mi familia no recibió ningún resultado
     - ☐ No he sabido nada sobre mis resultados
     - ☐ Planeo hablar sobre mis resultados con mi padre(s), pero todavía no lo he hecho
     - ☐ No tengo interés por conocer mis resultados
     - ☐ Otro [PRG: Por favor explica: FREE TEXT]

[PRG: If "No tengo interés por conocer mis resultados" selected]: "**¿Por qué no quieres conocer los resultados de tus pruebas genéticas?**"

2. **¿Cómo te enteraste sobre los resultados de tus pruebas genéticas? Selecciona todas las que correspondan.**
   - ☐ Estaba presente cuando la consejera genética del estudio se reunió con mi padre(s) para revisar los resultados de las pruebas.
   - ☐ Mi oncólogo me contó a mí y a mi padre(s) sobre los resultados de mis pruebas genéticas.
   - ☐ Otro médico o enfermera me contó a mí y a mi padre(s) sobre los resultados de mis pruebas genéticas.
   - ☐ Conversé con mi oncólogo, consejera genética, u otro médico sobre los resultados de mis pruebas genéticas **sin** la presencia de mi padre(s).
   - ☐ Leí la carta y/o el reporte que fue enviado a mi familia donde se explicaban los resultados.
   - ☐ Mi padre(s) me contó sobre los resultados de mis pruebas genéticas
   - ☐ Otro [PRG: FREE TEXT]

Cuéntanos cómo te sentiste al recibir los resultados de tus pruebas genéticas.

	Definitivamente no estoy de acuerdo	No estoy de acuerdo	Neutral	Estoy de acuerdo	Definitivamente estoy de acuerdo	No Aplica
3. Me trataron con sensibilidad y respeto	○	○	○	○	○	○
4. El equipo clínico se aseguró de que yo entendiera la información	○	○	○	○	○	○
5. Sentí que tenía la información y el apoyo disponibles para responder cualquier pregunta que tuviera después de recibir mis resultados genéticos.	○	○	○	○	○	○
6. Me sentí cómodo haciendo preguntas y diciendo qué me preocupó						

7. ¿Qué tan bien entiendes los resultados de tus pruebas?

- ○ Nada
- ○ Un poco
- ○ Regular
- ○ Bastante
- ○ Extremadamente
- ○ No aplica— no he visto mis resultados y no he hablado con alguien sobre ellos

Las siguientes preguntas indagan sobre cómo tú y tu familia toman decisiones sobre el cuidado de tu cáncer en general, y cómo se adoptó la decisión de participar en el estudio KidsCanSeq.

8. ¿Cuál de las siguientes afirmaciones describe mejor <u>cómo preferirías</u> tomar decisiones sobre el cuidado de tu cáncer?

- ○ Prefiero hacer yo mismo la selección definitiva de qué tratamiento recibiré.
- ○ Prefiero hacer yo mismo la selección definitiva de qué tratamiento recibiré después de considerar seriamente la opinión de mi padre(s).
- ○ Mi padre(s) y yo preferimos compartir la responsabilidad de decidir cuál tratamiento es el mejor para mí.
- ○ Prefiero que mi padre(s) tome la decisión final sobre mi tratamiento después de considerar seriamente mi opinión.
- ○ Prefiero dejar todas las decisiones relativas a mi tratamiento en manos de mi padre(s).

9. ¿Cuál de las siguientes afirmaciones describe mejor cómo se toman <u>realmente</u> las decisiones sobre el cuidado de tu cáncer?

- ○ Yo mismo hago la selección definitiva de qué tratamiento recibiré.
- ○ Yo mismo hago la selección definitiva de mi tratamiento después de considerar seriamente la opinión de mi padre(s).
- ○ Mi padre(s) y yo compartimos la responsabilidad de decidir cuál tratamiento es el mejor para mí.
- ○ Mi padre(s) toma la decisión final sobre mi tratamiento después de considerar seriamente mi opinión.
- ○ Dejo todas las decisiones relativas a mi tratamiento en manos de mi padre(s).

10. Por favor clasifica qué tan importantes son cada uno de los siguientes puntos para ti; desde Nada importante a Muy importante.

Al tomar decisiones sobre el cuidado de mi cáncer, para mí es importante que…

	Nada importante	**No muy importante**	**Importante**	**Muy importante**
Mis ideas se consideren en igual medida que las de mi médico	○	○	○	○
Haya tiempo suficiente para hacer preguntas	○	○	○	○
Mi médico y yo discutamos las diferentes opciones de tratamiento detalladamente	○	○	○	○
Ser capaz de discutir las diferentes opciones de tratamiento con mi médico en detalle	○	○	○	○
Mi médico y yo seleccionemos juntos una opción de tratamiento	○	○	○	○
Conocer los beneficios de las opciones de tratamiento individuales	○	○	○	○
Saber cuál opción de tratamiento es la mejor	○	○	○	○
Sentirme incluido en la decisión del tratamiento	○	○	○	○

	Nada importante	No muy importante	Importante	Muy importante
Sentir una responsabilidad compartida por mi tratamiento	○	○	○	○

Las siguientes preguntas solo se refieren a tu decisión de participar en el estudio KidsCanSeq. Estas preguntas no se refieren a cómo generalmente tomas decisiones sobre tu atención para el cáncer.

11. ¿Cómo se tomó la decisión de que participaras en el Estudio KidsCanSeq?

- ○ Yo tomé la decisión de participar
- ○ Yo tomé la decisión de participar después de considerar seriamente la opinión de mi padre(s)
- ○ Mi padre(s) y yo tomamos la decisión juntos
- ○ Mi padre(s) tomó la decisión de participar después de considerar seriamente mi opinión
- ○ Mi padre(s) tomó la decisión de participar

12. ¿Qué tan satisfecho estuviste con el papel que tuviste en la decisión de participar en el estudio KidsCanSeq y recibir pruebas genéticas?

- ○ Muy satisfecho
- ○ Algo satisfecho
- ○ Algo insatisfecho
- ○ Muy insatisfecho

Nos gustaría conocer de qué manera crees que las pruebas genéticas son útiles. Estamos interesados en tu perspectiva y no hay respuestas correctas o incorrectas.

Las pruebas genéticas que recibí:

	Definitivamente no estoy de acuerdo	No estoy de acuerdo	Neutral	Estoy de acuerdo	Definitivamente estoy de acuerdo
13. Pueden ayudar a tomar decisiones si mi cáncer regresa	○	○	○	○	○
14. Identificaron una causa de mi cáncer	○	○	○	○	○
15. Identificaron mi posibilidad de desarrollar una enfermedad(es) distinta del cáncer	○	○	○	○	○
16. Pueden cambiar qué tratamiento recibo por problemas médicos	○	○	○	○	○

a futuro que no están relacionados con el cáncer					
17. Pueden cambiar los medicamentos que tomo y que no son para el cáncer	○	○	○	○	○
18. Pueden influir en mis decisiones a futuro sobre si tengo hijos o no	○	○	○	○	○
19. Pueden llevar a los miembros de mi familia a hacerse pruebas genéticas o de cáncer	○	○	○	○	○
20. Me dieron información que yo deseo.	○	○	○	○	○
21. Me dieron tranquilidad.	○	○	○	○	○
22. Pueden dejarme a planear mejor el futuro.	○	○	○	○	○

Por favor cuéntanos qué piensas sobre estas afirmaciones.

	Definitivamente no estoy de acuerdo	**No estoy de acuerdo**	**Neutral**	**Estoy de acuerdo**	**Definitivamente estoy de acuerdo**
23. Me siento cómodo dejando que los investigadores usen mi información genética si ellos no usan mi nombre	○	○	○	○	○
24. Mi oncólogo me conoce lo suficiente como para ayudarme a entender mi información genética	○	○	○	○	○
25. Confío en los médicos que hacen	○	○	○	○	○

investigación clínica					
26. Confío en mi oncólogo/equipo de oncología	○	○	○	○	○
27. Me ha costado lidiar con mi información genética.	○	○	○	○	○
28. Me preocupa la privacidad de mi información genética	○	○	○	○	○
29. Me preocupa ser tratado de forma injusta debido a mi información genética. [PRG: if "Estoy de acuerdo" or "Definitivamente estoy de acuerdo":] ¿Qué tipo de tratamiento injusto te preocupa? Selecciona todas las que correspondan: ☐ Relacionado con el trabajo ☐ Financiero (por ejemplo, no poder obtener un préstamo bancario) ☐ Social ☐ Otro, por favor explica: [PRG: FREE TEXT]	○	○	○	○	○

30. En los últimos 12 meses, ¿tú y tu padre y/o tu oncólogo han conversado sobre la posibilidad de estar más a cargo de las decisiones relacionadas con tu salud?

- ○ No
- ○ Sí [PRG Checkbox if "Sí" selected: **¿Con quién has hablado?**
  - ○ Mi padre(s)
  - ○ Mi oncólogo(s)
  - ○ Mi padre(s) y mi oncólogo(s)

31. ¿También hablas inglés?

- ○ Sí [PRG: If selected, show next Q]
- ○ No

32. ¿Qué tan bien hablas inglés?

- ○ Hablo inglés perfectamente bien (Soy bilingüe o un hablante nativo de inglés)
- ○ Muy bien
- ○ Bien
- ○ No lo hablo bien

33. ¿En qué idioma prefieres hablar con tus doctores?

- ○ Inglés
- ○ Español
- ○ Me siento IGUAL de cómodo hablando en inglés o en español con mis doctores sobre mi atención médica

34. ¿En qué idioma prefieres hablar con tu padre(s) sobre tu atención médica?

- ○ Inglés
- ○ Español
- ○ Me siento IGUAL de cómodo hablando en inglés o en español con mi padre(s) sobre mi atención médica

35. ¿Alguna vez has tenido que traducir información médica para tu padre(s) en un ambiente clínico?

- ○ Sí
- ○ No [PRG: END SURVEY with SUBMIT instructions and THANK YOU]

[PRG: If "Sí" selected in above Q:] **¿Con qué frecuencia has tenido que traducir información médica para tu padre(s) en un ambiente clínico?**

- ○ Siempre
- ○ A menudo
- ○ A veces
- ○ Ocasionalmente
- ○ Nunca

[PRG: If "Sí" selected in above Q:] **¿Qué tan cómodo te sientes teniendo que traducir información médica para tu padre(s) en un ambiente clínico?**

- ○ Muy cómodo
- ○ Algo cómodo
- ○ Algo incómodo
- ○ Muy incómodo

Nos gustaría enviarle una tarjeta de regalo de $25 como agradecimiento por completar esta encuesta.

Si deseas una tarjeta de regalo de $25, ingrese tu NOMBRE Y APELLIDO COMPLETO y tu CORREO ELECTRÓNICO a continuación para que podamos enviársela electrónicamente. Tus respuestas se mantendrán confidenciales. Puede tomar hasta una semana para que reciba tu tarjeta.

POR FAVOR TENGA EN CUENTA: solo podemos enviar tu tarjeta de regalo si proporciona tu nombre, apellido, y correo electrónico.

Si tiene alguna pregunta sobre tu tarjeta de regalo, no recibe tu tarjeta de regalo o tienes problemas para activarla o utilizarla, puede comunicarse con Jill Robinson a jill.robinson@bcm.edu o al (713) 798-5848.

Nombre: FREE TEXT
Apellido: FREE TEXT
Correo electrónico: FREE TEXT
Ingrese tu correo electrónico nuevamente para confirmar: FREE TEXT

¡Gracias por participar el en Estudio KidsCanSeq y completer esta encuesta!

Appendix O: Organizational Readiness to Change Assessment (ORCA)

Organizational Readiness to Change Assessment (ORCA). An instrument to assess organizational readiness to change has been developed in the CSER consortium to measure participating clinical site's readiness to integrate genomic sequencing technologies into their clinical workflow. Each CSER project site is being asked to administer an anonymous survey to contribute to this CSER Consortium cross-site project. The ORCA is designed to evaluate the potential for healthcare systems, hospitals, and clinics to adapt when new healthcare practices and clinical services are introduced. It is hypothesized that this measure will help to understand the landscape for implementing genomic sequencing in medical systems.

To complete this activity for our KidsCanSeq study, we will be contacting 6-10 healthcare leaders at each of our KCS sites (6) to complete the ORCA. We will be contacting participants by email with a generic email link to an online version of the survey. The survey will ask participants questions about contextual factors, such as clinical experience, culture, and readiness to change (see below for questions). The survey will not collect identifying information besides general questions about their type of position, and the survey system will collect which of the six KCS site the participant is from. No other personal or identifiable information will be solicited in the survey or collected by the survey system. Participants will not receive compensation for their participation.

We plan to contact up to 20 participants at our larger sites (Texas Children's, Baylor College of Medicine, Cook Children's Medical Center, Children's Hospital of San Antonio, University of Texas Health Science Center at San Antonio), and up to 10 participants at our smaller sites (Vannie Cook). In total, we plan to contact a maximum of 110 people. Our goal is to receive 6-10 responses from each of our 6 sites, for an overall target of 36-60 respondents. This will not achieve sufficient statistical power for local analysis, but will provide descriptive statistics and will contribute to the overall CSER cross-site analysis.

Survey data will be sent to and analyzed by the CSER Coordinating Center at the University of Washington as part of the existing consortium data sharing agreement. Data analysis will include examining the distributions of the scores for items, subscales, and total score. For each, measures of central tendency (e.g., mean, median, mode) and variation (e.g., range, variance, standard deviation) will be calculated. Descriptive statistics will be examined within each CSER site (n=6) as well as across all sites. CSER ORCA data will be compared to historic ORCA data from the literature on organizational readiness to change. In addition, correlational analyses may be conducted to examine the relationship between total ORCA scores and recruitment and retention rates in CSER projects, as well as the relationship between the ORCA scores and uptake of genome sequencing broadly at CSER sites during the project period.

Please see the ORCA survey questions below:

Thank you for taking time to answer the following questions.

You are being asked to fill out the following measure because your medical site is participating in Baylor College of Medicine's Texas KidsCanSeq project, which is a research study that is part of the Clinical Sequencing Evidence-Generating Research (CSER) consortium. The CSER consortium is a partnership of 6 research projets across the country that seeks to engage underrepresented populations in genomic research and to implement genome sequencing in clinical settings.

The following questions are intended to seek your perceptions on the readiness of your health care system and clinics to use and implement genomic sequencing.

The position I occupy at my facility/site is considered:
(Check one. If multiple apply, please select the position that describes the activities which take the majority of your time.)

- ☐ Executive Team Member
  (examples: Chief Executive Officer, Chief Operating Officer, Chief Financial Officer)
- ☐ Clinical Supervisor or Manager
  (examples: Clinical Service Chief, Laboratory Director, Nurse Manager, Attending)
- ☐ Staff Clinician
  (examples: physician, nurse, social worker, rehabilitation therapist)

I am currently working to, or directly oversee employees working to implement CSER related activities at my site/facility. (check one):

- ☐ Yes
- ☐ No

ORCA	Strongly disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. Senior Leadership/Clinical management in your organization reward clinical innovation and creativity to improve patient care.	1	2	3	4	5
2. Senior Leadership/Clinical management in your organization solicit opinions of clinical staff regarding decisions about patient care.	1	2	3	4	5
3. Senior Leadership/Clinical management in your organization seek ways to improve patient	1	2	3	4	5

	education and increase patient participation in treatment.					
4.	Senior leadership/Clinical management in your organization provide effective management for continuous improvement of patient care.	1	2	3	4	5
5.	Senior leadership/Clinical management in your organization clearly define areas of responsibility and authority for clinical managers and staff.	1	2	3	4	5
6.	Senior leadership/Clinical management in your organization promote team building to solve clinical care problems.	1	2	3	4	5
7.	Senior leadership/Clinical management in your organization promote communication among clinical services and units.	1	2	3	4	5
8.	Staff Members in your organization have a sense of personal responsibility for improving patient care and outcomes.	1	2	3	4	5
9.	Staff members in your organization cooperate to maintain and improve effectiveness of patient care.	1	2	3	4	5
10.	Staff members in your organization are willing to innovate and/or experiment to improve clinical procedures.	1	2	3	4	5
11.	Staff members in your organization are receptive to changes in clinical processes.	1	2	3	4	5
12.	Opinion leaders in your organization believe that current practice patterns can be improved.	1	2	3	4	5
13.	Opinion leaders in your organization encourage and support changes in	1	2	3	4	5

practice patterns to improve patient care.					
14. Opinion leaders in your organization are willing to try new clinical protocol.	1	2	3	4	5
15. Opinion leaders in your organization work cooperatively with senior leadership/clinical management to make appropriate changes.	1	2	3	4	5
16. When there is agreement that change needs to happen, in general your organization has the necessary support in terms of budget or financial resources.	1	2	3	4	5
17. When there is agreement that change needs to happen, in general your organization has the necessary support in terms of training.	1	2	3	4	5
18. When there is agreement that change needs to happen, in general your organization has the necessary support in terms of facilities.	1	2	3	4	5
19. When there is agreement that change needs to happen, in general your organization has the necessary support in terms of staffing.	1	2	3	4	5