

Attachment 4: Parent Report (for children ages 4-17)

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Questions from national surveys and previously validated measures were prioritized for inclusion in the survey.

Question sources for the **parent-report survey** include the following instruments:

- National Survey of Children’s Health (NSCH) https://www.census.gov/content/dam/Census/programs-surveys/nsch/tech-documentation/questionnaires/2023/2023_NSCH-T3_FINAL.pdf
- National Health Interview Survey (NHIS) (<https://www.cdc.gov/nchs/nhis/>)
- SEED Follow-Up Survey <https://www.cdc.gov/autism/seed/follow-up.html>
- National Survey on the Diagnosis and Treatment of ADHD and Tourette syndrome (NS-DATA) https://ftp.cdc.gov/pub/Health_Statistics/NCHS/slits/ns_data/NS_DATA_Questionnaire.pdf

Additionally, there will be a 2-part clinical assessment (the clinical assessment is for the child, but the parent will provide information and be present, so we are including the forms here, and have included these assessments as part of the burden calculation for both the parent and the child).

- a. Ask Suicide Screening Questions (ASQ)
- b. Yale Global Tic Severity Scale (YGTSS)

We were mindful of the benefits of using previously tested and/or approved questions for adoption in our survey. All above surveys and instruments underwent extensive pilot and field testing and/or were previously approved and fully implemented in previous studies. Moreover, many of the questions we used are from surveys of nationally representative samples of US children and adults. This holds an added benefit of allowing us to compare data collected as part of this project to external prevalence rates for health indicators in the general U.S. population. In compiling questions into a single survey, we made only minor revisions to some of these existing questions. For example, in our survey we revised a question from CPS that referred to disability generally to ask about tic disorders, specifically. We also added mention of mental health care, specifically, to questions on healthcare as this has been reported as a major area of impact for individuals with tic disorders.

We have noted where each survey question originated (in the “Taken From” column). We have also annotated whether modifications were made using **yellow highlight**. New questions and answers are **highlighted in blue**.

A. Date of Birth and Race/ethnicity

Section Intro	Taken From
Completing the survey is voluntary. If you are not comfortable answering a question, just leave it blank.	Revised from a previous project.

Proposed Question	Response options	Taken From
Note: Today's date and the time stamp will be automatically populated by REDCap, and will not be seen by respondents. Today's date will be used to calculate age to make sure individual's are completing the correct form, and the time will be used in any notifications (if they are completing the wrong form or indicate self-harm or suicide) so the project staff will know which respondent endorsed those items (if multiple people are completing the form at the same time). Age will also not be seen by the respondent.		
What is this child's date of birth?	Month/Day/Year	Age is calculated in REDCap based on today's date and response to this question. If the child is over 18, the parent will receive a message to contact study staff for the correct form.

Please answer the following questions about this child.

Proposed Question	Response options	Taken From
What is this child's race and/or ethnicity? Select all that apply.	▪ American Indian or Alaska Native. For example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya, etc. ▪ Asian. For example, Chinese, Asian Indian, Filipino, Vietnamese, Korean, Japanese, etc. ▪ Black or African American. For example, African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali, etc. ▪ Hispanic or Latino. For example, Mexican, Puerto Rican, Salvadoran, Cuban, Dominican, Guatemalan, etc. ▪ Middle Eastern or North African. For example, Lebanese, Iranian, Egyptian, Syrian, Iraqi, Israeli, etc.	HHS/OMB approved method to ask R/E questions.

	▪ Native Hawaiian or Pacific Islander. For example, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, Marshallese, etc. ▪ White. For example, English, German, Irish, Italian, Polish, Scottish, etc.	
[If the respondent skipped any questions in this section, they will receive the following message:] You skipped one or more questions on this page. Please review and complete the question(s) before going to the next page. If you intentionally skipped the question(s), you can go to the next page.		

B. Co-occurring (text not shown – section continues from above with first question)

Questions and Response Options				Taken From
Has a doctor or other health care provider EVER told you that this child has:		Question B: Does this child currently have the condition? <i>[Skip logic: Only those who respond "Yes" to previous question will be asked Question B]</i>	Question C: Would you describe it as mild, moderate or severe? <i>[Skip logic: Only those who respond "Yes" to question B will be asked Question C]</i>	Stem is from NHIS. Follow up adapted from NSCH, NS-DATA, or NHIS.
An anxiety disorder, such as generalized anxiety disorder, panic disorder, or a phobia? Anxiety is a feeling of constant worrying. Children with severe anxiety problems may be diagnosed as having anxiety disorders.	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NS-DATA with minor edit to change "another" to "an"
Depression <i>Some common types of depression include major depression (or major depressive disorder), bipolar depression, dysthymia, post-partum depression, and seasonal affective disorder.</i>	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NSCH. Help text from NHIS.
Autism or Autism Spectrum Disorder? <i>Include diagnoses of Asperger's Disorder or Pervasive Developmental Disorder (PDD).</i>	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NSCH

Attention Deficit Disorder or Attention-Deficit/Hyperactivity Disorder, that is, ADD or ADHD?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Mild ☐ Moderate ☐ Severe	NSCH
Obsessive-compulsive disorder or OCD? <i>Children with OCD feel the need to check things repeatedly, or have certain thoughts or perform routines and rituals over and over.</i>	☐ Yes ☐ No	☐ Yes ☐ No	☐ Mild ☐ Moderate ☐ Severe	NS-DATA, NHIS (pulled from anxiety question).
Post-traumatic stress disorder or PTSD?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Mild ☐ Moderate ☐ Severe	From NHIS question that combined a number of anxiety disorders.
Substance use disorder? <i>Substance abuse is the frequent use of substances such as drugs that can be physically dangerous and can potentially lead to legal problems and frequent social or interpersonal problems.</i>	☐ Yes ☐ No	☐ Yes ☐ No	☐ Mild ☐ Moderate ☐ Severe	NS-DATA (deleted help text because the question is about substance use disorder and the help text is about substance abuse)
Frequent or severe headaches, including migraine?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Mild ☐ Moderate ☐ Severe	NSCH
A sleep disorder? <i>Examples of sleep disorders include sleep apnea, insomnia, and narcolepsy.</i>	☐ Yes ☐ No	☐ Yes ☐ No	☐ Mild ☐ Moderate ☐ Severe	NS-DATA
Eating disorder?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Mild ☐ Moderate ☐ Severe	SEED follow-up survey, with addition of severity question.
	☐	☐	☐	
A concussion or brain injury? <i>A concussion or brain injury is when a blow or jolt to the head causes problems such as headaches, dizziness, being dazed or confused, difficulty remembering or concentrating, vomiting, blurred vision, changes in mood or behavior, or being knocked out.</i>	☐ Yes ☐ No			Adapted from NSCH. <i>NSCH first asks about whether they sought care, and then about if they were told. Also, addition of severity question</i>

Questions and Response Options				Taken From
Has a doctor, other health care provider, or educator EVER told you that this child has: <i>Examples of educators are teachers and school nurses.</i>		Question B: Does this child currently have the condition? [Skip logic: Only those who respond "Yes" to previous question will be asked Question B]	Question C: Would you describe it as mild, moderate or severe? [Skip logic: Only those who respond "Yes" to Question B will be asked Question C]	NSCH
Behavioral or conduct problems?	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NSCH
Developmental delay?	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NSCH
Intellectual disability (formerly known as mental retardation)?	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NSCH
Speech disorder?	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NSCH <i>Adapted: split out into two questions (speech and language separate)</i>
Language disorder?	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NSCH <i>Adapted: split out into two questions (speech and language separate)</i>
Learning disability?	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NSCH

Questions and Response Options		Taken From	
Has a doctor or other health care provider told you that this child currently has:			
a. Allergies (such as food, drug, insect, seasonal, or other)?	▪ Yes ▪ No	NSCH	
b. Asthma?	▪ Yes ▪ No	NSCH	
c. Autoimmune disease (such as Type 1 Diabetes, Celiac, or Juvenile Idiopathic Arthritis)?	▪ Yes ▪ No	NSCH	
d. Type 2 Diabetes?	▪ Yes ▪ No	NSCH	
e. Epilepsy or seizure disorder?	▪ Yes ▪ No	NSCH	
Questions and Response Options		Taken From	
Has this child ever shown extreme expression of anger, often to the point of uncontrollable rage that is disproportionate to the situation at hand?	Question B: Does this child currently show extreme expression of anger? [Skip logic: Only those who respond “Yes” to previous question will be asked Question B]	Question C: Would you describe it as mild, moderate, or severe? [Skip logic: Only those who respond “Yes” to question B will be asked Question C]	Adapted from NS-DATA question on intermittent explosive disorder Intermittent explosive disorder? [HELP TEXT: Intermittent explosive disorder is a behavioral disorder characterized by extreme expression of anger, often to the point of uncontrollable rage that is disproportionate to the situation at hand?]
▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	
During the past 12 months, how many times did this child do something to purposely hurt themselves without wanting to die, such as cutting or burning themselves on purpose?	• 0 times • 1 time • 2 or 3 times • 4 or 5 times • 6 or more times		Edited from YRBS self-report to parent-report
Has this child ever had sensory processing problems? <i>For example, being hypersensitive (over-responsive) to certain sensations (like certain lights, sounds, touch, tastes, or smells) or hyposensitive (under-responsive) and seek</i>	▪ Yes ▪ No		Edited from SEED question asking about sensory integration disorder, which isn't recognized as a disorder, so we are rephrasing as problems the adult might be experiencing.

out sensory input, to the point that it causes distress.			
[If the respondent skipped any questions in this section, they will see the following message:] You skipped one or more questions on this page. Please review and complete the question(s) before going to the next page. If you intentionally skipped the question(s), you can go to the next page.			

C. The next questions ask about treatment for tic disorders and related conditions.

Question	Response Options	Taken From
The next questions ask about medications this child may be taking for a tic disorder or related conditions. <i>Related conditions include things like ADHD, OCD, anxiety, depression, behavior issues, or other mental health conditions.</i>		NS-DATA (TS_C1_1). NS-DATA only asks about Tourette syndrome but we are interested in tic disorders more generally, and many medications overlap for what they are being used to treat, so asking about other related conditions too.
Has this child ever taken medication for a tic disorder or related conditions?	- Yes [Go to TS_C1_2]; - No [Go to TS_C3_1];	NS-DATA TS_C1_1
At what age did this child first start taking medication for a tic disorder or related conditions?	Free text	NS-DATA TS_C1_2
Is this child currently taking medication for a tic disorder or related conditions?	- Yes [Go to TS_C1_4]; - No [Go to TS_C1_5 TS_C3_1];	NS-DATA TS_C1_3
What medications does this child currently take for a tic disorder or related conditions? Please list all.	Free text	NS-DATA TS_C1_4_NEW <i>Original question had multiple choice/select all response options (phone survey).</i>
Who usually makes sure this child takes their medication for a tic disorder or related conditions?	- A parent or guardian - Another family member or adult - The child - Other person (Please specify relationship of other person)	NS-DATA TS_C2_1 <i>Original response options:</i> (1) A PARENT OR GUARDIAN

		(2) ANOTHER FAMILY MEMBER (3) SOMEONE AT SCHOOL (4) A BABYSITTER OR NANNY (5) THE CHILD (6) OTHER PERSON
If you selected "other" for the previous question, please specify who usually makes sure this child takes their medication for a tic disorder or related conditions:	Free text	Added for REDCap programming. <i>This will only be asked if selected "other" for previous question, and a space will appear in previous question. This text will not show.</i>
In the past 12 months, was there a time when this child resisted taking their medication for a tic disorder or related conditions? Do not include resistance solely due to physical reasons such as being unable to swallow a pill.	▪ Yes ▪ No	NS-DATA TS_C2_2
The next questions ask about other treatments for a tic disorder or related conditions. <u>Related conditions</u> include things like ADHD, OCD, anxiety, depression, behavior issues, or other mental health conditions.		NS-DATA
Has this child ever received comprehensive behavioral intervention for tics (CBIT) or habit reversal therapy for a tic disorder?	▪ Yes [GO TO TS_C3_1A;] ▪ No [GO TO TS_C3_2]; ▪ Don't know [GO TO TS_C3_2]	NS-DATA TS_C3_1
Is this child currently receiving comprehensive behavior intervention for tics (CBIT) or habit reversal therapy for a tic disorder?	▪ Yes [GO TO TS_C3_1B] ▪ No [GO TO TS_C3_2]; ▪ Don't Know	NS-DATA TS_C3_1A
Has this child ever received school-based behavioral treatment, support, or accommodation for a tic disorder or related conditions? <i>Do not include CBIT or habit reversal therapy.</i>	▪ Yes [GO TO TS_C3_2A]; ▪ No [GO TO TS_C3_3]; ▪ Don't Know [GO TO TS_C3_3];	NS-DATA TS_C3_2
Is this child currently receiving school-based behavioral treatment, support, or accommodation for a tic disorder or related conditions? <i>Do not include CBIT or habit reversal therapy.</i>	▪ Yes ▪ No ▪ Don't Know	NS-DATA TS_C3_2A

Has this child ever received behavioral treatment based outside of school for a tic disorder or related conditions ? <i>Do not include CBIT or habit reversal therapy.</i>	- Yes [GO TO TS_C3_3A] - No [GO TO TS_C3_4] - Don't Know [GO TO TS_C3_4]	NS-DATA TS_C3_3
Is this child currently receiving behavior treatment based outside of school for a tic disorder or related conditions ? <i>Do not include CBIT or habit reversal therapy.</i>	- Yes - No - Don't Know	NS-DATA TS_C3_3A
Has this child ever received any other treatment for a tic disorder or related conditions ?	- Yes [GO TO Follow up]; - No [GO TO TS_C3_5]; - Don't Know [GO TO TS_C3_5]	NS-DATA TS_C3_4
Please specify any other treatment this child has ever received for a tic disorder or related conditions:	Free text	Note: This will only be asked if selected "YES" for previous question
Is this child currently receiving any other treatment for a tic disorder or related conditions ?	- Yes [GO TO Follow up] - No [GO TO TS_C3_5]; - Don't Know [GO TO TS_C3_5]	NS-DATA TS_C3_4A
Please specify any other treatment this child is currently receiving for a tic disorder or related conditions:	Free text	Note: This will only be asked if selected "YES" for previous question
Does this child currently have a formal educational plan, such as an Individualized Education Program, also called an IEP or a 504 plan?	- Yes [GO TO TS_C3_6]; - No [GO TO TS_C4_3] - Don't Know [GO TO TS_C4_3]	NS-DATA TS_C3_5
Which one is it, an IEP or a 504 plan?	- IEP 504 - Something else - Both IEP and 504 plan	NS-DATA TS_C3_6
Overall, how satisfied are you with this child's tic disorder treatment and management? Would you say you are very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied?	- Very satisfied - Somewhat satisfied - Somewhat dissatisfied - Very dissatisfied	NS-DATA TS_C4_3 Changed "Tourette syndrome" to "tic disorder"
In the <u>past year</u> , has your child received any of the following for any mental, emotional, or behavioral problem, across settings (school, doctor's office)? Select all that apply.	- Parent training - Social skills training - Cognitive behavioral therapy - Counseling (for example, talk therapy or psychotherapy) - Other (Please specify):	PLAY-MH (replaced "his/her" with "any") <i>Each of these treatment types were asked as separate questions – propose combining with "select</i>

	None of these [REDCap is programmed so they cannot choose “none of these” and another option]	<i>all that apply” response options.</i>
If you selected “other” for the previous question, please specify:	Free text	Note: <i>This will only be asked if “Other” selected for previous question</i>
[If the respondent skipped any questions in this section, they will receive the following message:] You skipped one or more questions on this page. Please review and complete the question(s) before going to the next page. If you intentionally skipped the question(s), you can go to the next page.		

D. The next questions ask about the transition from pediatric to adult health care. (for parents of children age 12-17 years only)

Proposed Question	Response Options	Taken From
1. Do any of this child’s doctors or other health care providers treat only children?	- Yes - No (skip to question 2)	NSCH
a. [If yes,] Have they talked with you about when this child will need to see doctors or other health care providers who treat adults?	- Yes - No	NSCH
2. Has this child’s doctor or other health care provider actively worked with this child to:		NSCH
a. Make positive choices about their health. <i>For example, by eating healthy, getting regular exercise, not using tobacco, alcohol or other drugs, or delaying sexual activity?</i>	- Yes - No - Don’t Know	NSCH
b. Gain skills to manage their health and health care. <i>For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications they may need?</i>	- Yes - No - Don’t Know	NSCH
c. Understand the changes in health care that happen at age 18. <i>For example, by understanding changes in privacy, consent, access to information, or decision-making?</i>	- Yes - No - Don’t Know	NSCH
3. Did you and this child receive a summary of your child’s medical history (for example, medical conditions, allergies, medications, immunizations)?	- Yes - No	NSCH
4. Have this child’s doctors or other health care providers worked with you and this child to create a plan of care to meet their health goals and needs?	- Yes - No (skip to question 5)	NSCH
a. [If yes,] Do you and this child have access to this plan of care?	- Yes - No	NSCH

b. Does this plan of care address transition to doctors and other health care providers who treat adults?	- Yes - No - No, this child already sees providers who treat adults	NSCH
5. Eligibility for health insurance often changes in young adulthood. Do you know how this child will be insured as they become an adult?	- Yes [If yes, skip to question 6] - No	NSCH
a. [If no,] Has anyone discussed with you how to obtain or keep some type of health insurance coverage as this child becomes an adult?	- Yes - No	NSCH
6. Do you have concerns about your child transitioning from pediatric to adult healthcare providers to provide care related to their tic disorder?	- Yes [if yes, skip to follow up a.] - No (skip next question; go to next section)	New
a. What are your main concerns?	Open ended (word limit: 125 words)	New
[If the respondent skipped any questions in this section, they will receive the following message:] You skipped one or more questions on this page. Please review and complete the question(s) before going to the next page. If you intentionally skipped the question(s), you can go to the next page.		

E. The next questions ask about this child's school attendance, your employment, and use of health care services.

Question	Response Options	Taken From
DURING THE PAST 12 MONTHS, about how many days did this child miss school because of illness or injury? <i>Include days missed from any formal home schooling.</i>	- No missed school days (skip next question) 1-3 days 4-6 days 7-10 days 11 or more days - This child was not enrolled in school (skip next question)	NSCH
DURING THE PAST 12 MONTHS, about how many days did this child miss school because of behavior, mood, or tic related concerns? <i>Include days missed from any formal home schooling.</i>	- No missed school days 1-3 days 4-6 days 7-10 days 11 or more days - This child was not enrolled in school	Adapted from NSCH
Which of the following best describes your current employment status?	- Employed full-time - Employed part-time - Working WITHOUT pay - Not employed but looking for work	NSCH

	▪ Not employed and not looking for work ▪ Retired	
Does this child have another parent or adult caregiver who lives in this household?	▪ Yes ▪ No	NSCH
If yes (will be coded to skip), Which of the following best describes this caregiver's current employment status?	▪ Employed full-time ▪ Employed part-time ▪ Working WITHOUT pay ▪ Not employed but looking for work ▪ Not employed and not looking for work ▪ Retired	NSCH
DURING THE PAST 12 MONTHS, have you or other family members...		NSCH
Left a job or taken a leave of absence because of this child's health or health conditions?	▪ Yes ▪ No	NSCH
Cut down on the hours you work because of this child's health or health conditions?	▪ Yes ▪ No	NSCH
Avoided changing jobs because of concerns about maintaining health insurance for this child?	▪ Yes ▪ No	NSCH
Including co-pays and amounts reimbursed from Health Savings Accounts (HSA) and Flexible Spending Accounts (FSA), how much money did you pay for this child's <u>medical, health, dental, and vision care</u> DURING THE PAST 12 MONTHS? <i>Do not include health insurance premiums or costs that were or will be reimbursed by insurance or another source.</i>	▪ \$0 (No medical or health-related expenses) ▪ \$1-\$249 ▪ \$250-\$499 ▪ \$500-\$999 ▪ \$1,000-\$5,000 ▪ More than \$5,000	NSCH
Including co-pays and amounts reimbursed from Health Savings Accounts (HSA) and Flexible Spending Accounts (FSA), how much money did you pay for this child's <u>mental health care including prescriptions and office visits</u> DURING THE PAST 12 MONTHS? <i>Do not include health insurance premiums or costs that were or will be reimbursed by insurance or another source.</i>	▪ \$0 (No medical or health-related expenses) ▪ \$1-\$249 ▪ \$250-\$499 ▪ \$500-\$999 ▪ \$1,000-\$5,000 ▪ More than \$5,000	NSCH
The next questions are about your family's medical bills. Include bills for doctors, dentists, hospitals, therapists, medication, equipment, and nursing home or home care.		NHIS
In the past 12 months, did anyone in your family have problems paying or were unable to pay any medical bills?	▪ Yes ▪ No	NHIS

Does anyone in your family currently have any medical bills that you are unable to pay at all?	- Yes - No	NHIS
If this child gets sick or has an accident, how worried are you that your family will be able to pay their medical bills? Are you very worried, somewhat worried, or not at all worried?	- Very worried - Somewhat worried - Not at all worried	NHIS, adapted to say "this child" instead of the name
During the past 12 months, has medical care BEEN DELAYED for this child because of the cost?	- Yes - No	NHIS, adapted to say "this child" instead of the name
During the past 12 months, was there any time when this child needed medical care, but DID NOT GET IT because of the cost?	- Yes - No	NHIS, adapted to say "this child" instead of the name
At any time in the past 12 months, did this child take prescription medication?	- Yes - No	NHIS, adapted to say "this child" instead of the name
During the past 12 months, did you DELAY filling a prescription for this child to save money?	- Yes - No	NHIS, adapted to say "this child" instead of the name
During the past 12 months, was there any time when this child needed prescription medication, but DID NOT GET IT because of the cost?	- Yes - No	NHIS, adapted to say "this child" instead of the name
During the past 12 months, has this child been DELAYED in getting counseling or therapy from a mental health professional because of the cost?	- Yes - No	NHIS, adapted to say "this child" instead of the name
During the past 12 months, was there any time when this child needed counseling or therapy from a mental health professional, but DID NOT GET IT because of the cost?	- Yes - No	NHIS, adapted to say "this child" instead of the name
During the past 12 months, has this child been DELAYED in getting counseling or therapy from a mental health professional because you couldn't get an appointment?	- Yes - No (skip next question)	Adapted from NHIS question above
[If yes,] How long was the delay?	- Less than 3 months 3-6 months 7-12 months - More than 12 months	New question
During the past 12 months, how many times has this child gone to a hospital emergency room about their health? <i>This includes emergency room visits that resulted in a hospital admission.</i>	Free text	NHIS (similar Q on NSCH)
During the past 12 months, has this child been hospitalized overnight?	- Yes - No	NHIS (similar Q on NSCH)

[If the respondent skipped any questions in this section, they will receive the following message:]
You skipped one or more questions on this page. Please review and complete the question(s) before going to the next page. If you intentionally skipped the question(s), you can go to the next page.

F. Please answer the following additional questions about this child.

Question	Response Options	Taken From
What is this child's sex?	- Male - Female	From HHS/OMB guidance. Edited for parent report.
Which of the following best represents how your child thinks of themselves?	- Gay (lesbian or gay) - Straight, this is not gay (or lesbian or gay) - Bisexual - Something else - I don't know the answer	HHS/OMB guidance. Edited for parent report
The next questions are about health insurance. Include health insurance obtained through employment or purchased directly as well as government programs like Medicare, Medicaid, and the Children's Health Insurance Program that provide medical care or help pay medical bills.		NHIS
Is this child covered by any kind of health insurance or some other kind of health care plan?	- Yes - No [skip next question]	NHIS
What kinds of health insurance or health care coverage does this child have? Is it...Private health insurance, Medicare, Medicare supplement, Medicaid, Children's Health Insurance Program or CHIP, military related health care including TRICARE, CHAMPUS, VA health care and CHAMP-VA, Indian Health Service, a state-sponsored health plan, or another government program? Select all that apply.	- Private health insurance - Medicare - Medigap - Medicaid - Children's Health Insurance Program (CHIP) - Military related health care: TRICARE (CHAMPUS) / VA health care / CHAMP-VA - Indian Health Service - State-sponsored health plan - Other government program - No coverage of any type	NHIS [REDCap is programmed so they cannot choose "no coverage of any type" and another option]
Does this child have any of the following?		NSCH
Serious difficulty concentrating, remembering, or making decisions	- Yes - No	NSCH

because of a physical, mental, or emotional condition		
Serious difficulty walking or climbing stairs	▪ Yes ▪ No	NSCH
Difficulty dressing or bathing	▪ Yes ▪ No	NSCH
Difficulty doing errands alone, such as visiting a doctor's office or shopping, because of a physical, mental, or emotional condition	▪ Yes ▪ No	NSCH
Deafness or problems with hearing	▪ Yes ▪ No	NSCH
Blindness or problems with seeing, even when wearing glasses	▪ Yes ▪ No	NSCH
[If the respondent skipped any questions in this section, they will receive the following message:] You skipped one or more questions on this page. Please review and complete the question(s) before going to the next page. If you intentionally skipped the question(s), you can go to the next page.		

Section Intro: The final section asks questions about you and your family.		
Question	Response Options	Taken From
How are you related to this child?	▪ Biological or adoptive parent ▪ Step-parent ▪ Grandparent ▪ Foster parent ▪ Other: Relative ▪ Other: non-Relative	NSCH
What is the HIGHEST level of school you have completed or the highest degree you have received?	▪ Never attended/kindergarten only ▪ Grade 1-11 ▪ 12th grade, no diploma ▪ GED or equivalent ▪ High school Graduate ▪ Some college, no degree ▪ Associate degree: occupational, technical, or vocational program ▪ Associate degree: academic program ▪ Bachelor's degree (Example: BA, AB, BS, BBA) ▪ Master's degree (Example: MA, MS, MEng, MEd, MBA) ▪ Professional school degree (Example: MD, DDS, DVM, JD) ▪ Doctoral degree (Example: PhD, EdD)	NHIS HHC.0350.00.1
What is your marital status?	▪ Married ▪ Not married, but living with a partner ▪ Never married	NSCH

	▪ Divorced ▪ Separated ▪ Widowed	
The following questions are about the address where you currently live. What is your current street address? Example: 123 Main Street	Free Text	New
What is the apartment or unit number (skip if none)? Example: Apt. 5a	Free text	
In what city do you currently live?	Free Text	
In what state do you currently live?	[Drop down menu to select one] Alabama Alaska Arizona Arkansas California Colorado Connecticut District of Columbia Delaware Florida Georgia Hawaii Idaho Illinois Indiana Iowa Kansas Kentucky Louisiana Maine Maryland Massachusetts Michigan Minnesota Mississippi Missouri Montana Nebraska Nevada New Hampshire New Jersey New Mexico New York North Carolina North Dakota Ohio Oklahoma	

	Oregon Pennsylvania Rhode Island South Carolina South Dakota Tennessee Texas Utah Vermont Virginia Washington West Virginia Wisconsin Wyoming Other (please specify)	
[if not one of 50 states or D.C.]: Specify other place (not US state) you live	Free text	New
What is your current zip code (for address above)?	Free text, validated in REDCap to match zip code format (5 numbers)	
How many people are living or staying at this address? <i>Include everyone who usually lives or stays at this address. Do NOT include anyone who is living somewhere else for more than two months, such as a college student living away or someone in the Armed Forces on deployment.</i>	Free text	NSCH
What is your best estimate of your total family income from all sources, before taxes, in the last year?	A. <\$15,000 B. \$15,000-\$24,999 C. \$25,000-49,999 D. \$50,000-74,999 E. \$75,000-99,999 F. \$100,000-149,999 G. \$150,000-199,999 H. \$200,000 or higher	NHIS Slightly different response categories than NHIS
Did anyone help you complete this survey?	▪ Yes, someone helped me, but I completed most of the survey on my own. ▪ Yes, someone helped me with all or most of the survey. ▪ No, I completed the survey on my own.	New
If you are interested in receiving project updates in the future, please enter your email address. You may decline to be re-contacted now or at any time in the future.	▪ Free text	New

[If the respondent skipped any questions in this section, they will receive the following message:]

You skipped one or more questions on this page. Please review and complete the question(s) before going to the next page. If you intentionally skipped the question(s), you can go to the next page.

Clinical Assessment

- a. Ask Suicide Screening Questions (ASQ) (ages 9 years and older)
- b. Yale Global Tic Severity Scale (YGTSS)

The clinical assessment is focused on the child but the parent will be present so the time is included in the parent assessment, and therefore these measures are included as part of the parent burden estimate and attached.

The following questions will be asked by a trained professional, not as part of the survey.

- a. Ask Suicide Screening Questions (ASQ)** (these are in a separate REDCap form since they are not part of the self-report survey; these questions will be asked by a healthcare provider or trained program staff member to individuals with tic disorders aged 9-26 years with possible input from parent for children 9-17 years.

Question	Response Options	Taken From
Note to person administering the ASQ: Please provide the following information to the respondent before asking the questions. <i>This survey asks about mental health and emotional well-being. If you answer that you have had suicidal thoughts or behaviors, or purposely tried to hurt yourself, we may inform your doctor or other clinic staff. This would be to ensure your safety and provide you with support and care.</i> <i>By completing this survey, you accept and consent to this protocol. If you have concerns or need immediate help, please tell the clinic staff.</i>		
1) In the past few weeks, have you wished you were dead?	▪ Yes ▪ No ▪ Refused to answer	ASQ
2) In the past few weeks, have you felt that you or your family would be better off if you were dead?	▪ Yes ▪ No ▪ Refused to answer	ASQ
3) In the past week, have you been having thoughts about killing yourself?	▪ Yes ▪ No ▪ Refused to answer	ASQ
4) Have you ever tried to kill yourself?	▪ Yes ▪ No ▪ Refused to answer	ASQ
[If yes to 4,] 4a) How? 4b) When?	Free text	ASQ
The patient answered "No" to questions 1 through 4; therefore, screening is complete, and it is not necessary to ask question #5. No intervention is necessary; however, clinical judgment can always override a negative screen. Do you want to ask the patient question #5 (Are you having thoughts of killing yourself right now?) or finish the ASQ?	▪ Ask question #5 ▪ Finish the ASQ	Incorporated from ASQ instructions, within skip pattern. ASQ instructions included below.
[If "Yes" or "Refused" to any of the above (Q1-Q4)] This patient is considered a positive screen. Ask question #5 to assess acuity. 5) Are you having thoughts of killing yourself right now?	▪ Yes ▪ No	ASQ

[If yes to Q5] 5b) Please describe:	Open ended	ASQ
[If yes to Q5] Patient is acute positive screen (imminent risk identified) Patient requires a STAT safety/full mental health evaluation. Patient cannot leave until evaluated for safety. Keep patient in sight. Remove all dangerous objects from room. Alert physician or clinician responsible for patient's care. Provide resources to all patients: 988 Suicide and Crisis Lifeline, 988 (call, text), https://988lifeline.org/ (and relevant local information)		
[If no to Q5] Patient is non-acute positive screen (potential risk identified). Patient requires a brief suicide safety assessment to determine if a full mental health evaluation is needed. If a patient (or parent/guardian) refuses the brief assessment, this should be treated as an "against medical advice" (AMA) discharge. Alert physician or clinician responsible for patient's care. Provide resources to all patients: 988 Suicide and Crisis Lifeline, 988 (call, text), https://988lifeline.org/		
Initials of person (staff/professional) completing ASQ	Open ended	
Overview of ASQ - this information is included above, within skip logic, and only included here for reference. <u>If patient answers "No" to all questions 1 through 4, screening is complete</u> (not necessary to ask question #5). No intervention is necessary (*Note: Clinical judgment can always override a negative screen). <u>If patient answers "Yes" to any of questions 1 through 4, or refuses to answer, they are considered a positive screen. Ask question #5 to assess acuity.</u> "Yes" to question #5 = acute positive screen (imminent risk identified) Patient requires a STAT safety/full mental health evaluation. Patient cannot leave until evaluated for safety. Keep patient in sight. Remove all dangerous objects from room. Alert physician or clinician responsible for patient's care. "No" to question #5 (but "Yes" or "Refused" to one of questions 1-4) = non-acute positive screen (potential risk identified) Patient requires a brief suicide safety assessment to determine if a full mental health evaluation is needed. If a patient (or parent/guardian) refuses the brief assessment, this should		ASQ

be treated as an "against medical advice" (AMA) discharge.

Alert physician or clinician responsible for patient's care.

Provide Resources to All Patients:

- 988 Suicide and Crisis Lifeline, Call or Text 988
- Visit <https://988lifeline.org> to chat

ID #:

Y G T S S
Yale Global Tic Severity Scale
Yale Child Study Center

October 1992 version

NAME:	TODAY'S DATE :	/	/
RATER:			

MOTOR TIC SYMPTOM CHECKLIST

Description of Motor Tic Symptoms. Motor tics usually begin in childhood and are characterized by sudden jerks or movements, such as forceful eye blinking or a rapid head jerk to one side or the other. The same tics seem to recur in bouts during the day and are worse during periods of fatigue and/or stress. Many tics occur without warning and may not even be noticed by the person doing them. Others are preceded by a subtle urge that is difficult to describe (some liken it to the urge to scratch an itch). In many cases it is possible to voluntarily hold back the tics for brief periods of time. Although any part of the body may be affected, the face, head, neck, and shoulders are the most common areas involved. Over periods of weeks to months, motor tics wax and wane and old tics may be replaced by totally new ones.

Simple motor tics can be described as a sudden, brief, "meaningless" movement that recurs in bouts (such as excessive eye blinking or squinting). Complex motor tics are sudden, stereotyped (i.e., always done in the same manner) semi-purposeful (i.e., the movement may resemble a meaningful act, but is usually involuntary and not related to what is occurring at the time) movements that involve more than one muscle group. There may often be a constellation of movements such as facial grimacing together with body movements. Some complex tics may be misunderstood by other people (i.e., as if you were shrugging to say "I don't know"). Complex tics can be difficult to distinguish from compulsions; however, it is unusual to see complex tics in the absence of simple ones. Often there is a tendency to explain away the tics with elaborate explanations (e.g., "I have hay fever that has persisted" even though it is not the right time of year). Tics are usually at their worst in childhood and may virtually disappear by early adulthood, so if you are completing this form for yourself, it may be helpful to talk to your parents, an older sibling, or a relative, as you answer the following questions.

- Age of **first** motor tics? _____ years old
- Describe **first** motor tic: _____
- Was tic onset sudden or gradual? _____
- Age of **worst** motor tics? _____ years old

Motor Tic Symptom Checklist

In the boxes on the left below, please check with a mark (x) the tics the patient

- 1) has **EVER** experienced
- 2) is **CURRENTLY** experiencing (during the past week)

State **AGE OF ONSET** (in years) if patient has had that behavior.

Also, in the tic descriptions below, please **circle** or **underline** the specific tics that the patient has experienced (circle or underline the words that apply).

[In Years]

Ever	Current	Age of onset	The patient has experienced, or others have noticed, involuntary and apparently purposeless bouts of:	Ver
-eye movements.				
			eye blinking, squinting, a quick turning of the eyes, rolling of the eyes to one side, or opening eyes wide very briefly.	
			eye gestures such as looking surprised or quizzical, or looking to one side for a brief period of time, as if s/he heard a noise.	
-nose, mouth, tongue movements, or facial grimacing.				
			nose twitching, biting the tongue, chewing on the lip or licking the lip, lip pouting, teeth baring, or teeth grinding.	
			broadening the nostrils as if smelling something, smiling, or other gestures involving the mouth, holding funny expressions, or sticking out the tongue.	
-head jerks/movements.				
			touching the shoulder with the chin or lifting the chin up.	
			throwing the head back, as if to get hair out of the eyes.	
-shoulder jerks/movements.				
			jerking a shoulder.	
			shrugging the shoulder as if to say "I don't know."	
-arm or hand movements.				
			quickly flexing the arms or extending them, nail biting, poking with fingers, or popping knuckles.	
			passing hand through the hair in a combing like fashion, or touching objects or others, pinching, or counting with fingers for no purpose, or writing tics, such as writing over and over the same letter or word, or pulling back on the pencil while writing.	
-leg, foot or toe movements.				
			kicking, skipping, knee-bending, flexing or extension of the ankles; shaking, stomping or tapping the foot.	
			taking a step forward and two steps backward, squatting, or deep knee-bending.	

Ever	Current	Age of onset	The patient has experienced, or others have noticed, involuntary and apparently purposeless bouts of:	Ver
------	---------	--------------	---	-----

-abdominal/trunk/pelvis movements.

			tensing the abdomen, tensing the buttocks.	
--	--	--	--	--

-other simple motor tics.

			Please write example(s):	

-other complex motor tics.

			touching	
			tapping	
			picking	
			evening-up	
			reckless behaviors	
			stimulus-dependent tics (a tic which follows, for example, hearing a particular word or phrase, seeing a specific object, smelling a particular odor). Please write example(s):	
			rude / obscene gestures; obscene finger / hand gestures.	
			unusual postures.	
			bending or gyrating, such as bending over.	
			rotating or spinning on one foot.	
			copying the action of another (echopraxia)	
			sudden tic-like impulsive behaviors. Please describe:	
			tic-like behaviors that could injure / mutilate others. Please describe:	
			self-injurious tic-like behavior(s). Please describe:	

-other involuntary and apparently purposeless motor tics (that do not fit in any previous categories).

			Please describe any other patterns or sequences of motor tic behaviors:	

Phonic (Vocal) Tics

Description of Phonic (or Vocal) Tic Symptoms Phonic tics usually begin in childhood, typically after motor tics have already started, but they can be the first tic symptoms. They are characterized by a sudden utterance of sounds such as throat clearing or sniffing. The same tics seem to recur in bouts during the day and are worse during periods of fatigue and / or stress. Many tics occur without warning and may not even be noticed by the person doing them. Others are preceded by a subtle urge that is difficult to describe (some liken it to the urge to scratch an itch). In many cases it is possible to voluntarily hold back the tics for brief periods of time. Over periods of weeks to months, phonic tics wax and wane and old tics may be replaced by totally new ones. Simple phonic tics are utterances of fast, meaningless sounds whereas complex phonic tics are involuntary, repetitive, purposeless utterances of words, phrases or statements that are out of context, such as uttering obscenities (i.e., coprolalia), or repeating over and over again what other people have said (i.e., echolalia). Complex tics can be difficult to distinguish from compulsions; however, it is unusual to see complex tics in the absence of simple ones. Often there is a tendency to explain away the tics with elaborate explanations (e.g., "I have hay fever that has persisted" even though it is not the right time of year). Tics are usually at their worst in childhood and may virtually disappear by early adulthood, so if you are completing this form for yourself, it may be helpful to talk to your parents, an older brother or sister, or older relative, as you answer the following questions.

- Age of **first** vocal tics? _____ years old.
- Describe **first** vocal tic: _____
- Was tic onset sudden or gradual? _____
- Age of **worst** vocal tics? _____ years old.

Phonic Tic Symptom Checklist

In the boxes on the left below, please check with a mark (x) the tics the patient

- 1) has **EVER** experienced
- 2) is **CURRENTLY** experiencing (during the past week)

State **AGE OF ONSET** (in years) if patient has had that behavior.

Also, in the tic descriptions below, please **circle** or **underline** the specific tics that the patient has experienced (circle or underline the words that apply).

[In Years]

Ever	Cur- rent	Age of onset	The patient has experienced, or others have noticed, bouts of involuntary and apparently purposeless utterance of:	Ver
			-coughing.	
			-throat clearing.	
			-sniffing.	
			-whistling.	
			-animal or bird noises.	
			-Other simple phonic tics. Please list:	
			-syllables. Please list:	
			-words. Please list:	
			-rude or obscene words or phrases. Please list:	
			-repeating what someone else said, either sounds, single words or sentences. Perhaps repeating what's said on TV (echolalia).	
			-repeating something the patient said over and over again (palilalia).	
			-other tic-like speech problems, such as sudden changes in volume or pitch. Please describe:	
			Describe any other patterns or sequences of phonic tic behaviors:	

SEVERITY RATINGS

NUMBER

	Motor	Phonic	
None	0	0	0
Single tic	0	0	1
Multiple discrete tics (2-5)	0	0	2
Multiple discrete tics (>5)	0	0	3
Multiple discrete tics plus at least one orchestrated pattern of multiple simultaneous or sequential tics where it is difficult to distinguish discrete tics	0	0	4
Multiple discrete tics plus several (>2) orchestrated paroxysms of multiple simultaneous or sequential tics that where it is difficult to distinguish discrete tics	0	0	5

FREQUENCY

	Motor	Phonic	
NONE No evidence of specific tic behaviors	0	0	0
RARELY Specific tic behaviors have been present during previous week. These behaviors occur infrequently, often not on a daily basis. If bouts of tics occur, they are brief and uncommon.	0	0	1
OCCASIONALLY Specific tic behaviors are usually present on a daily basis, but there are long tic-free intervals during the day. Bouts of tics may occur on occasion and are not sustained for more than a few minutes at a time.	0	0	2
FREQUENTLY Specific tic behaviors are present on a daily basis. tic free intervals as long as 3 hours are not uncommon. Bouts of tics occur regularly but may be limited to a single setting.	0	0	3
ALMOST ALWAYS Specific tic behaviors are present virtually every waking hour of every day, and periods of sustained tic behaviors occur regularly. Bouts of tics are common and are not limited to a single setting.	0	0	4
ALWAYS Specific tic behaviors are present virtually all the time. Tic free intervals are difficult to identify and do not last more than 5 to 10 minutes at most.	0	0	5

INTENSITY

	Motor	Phonic	
ABSENT	0	0	0
MINIMAL INTENSITY Tics not visible or audible (based solely on patient's private experience) or tics are less forceful than comparable voluntary actions and are typically not noticed because of their intensity.	0	0	1
MILD INTENSITY Tics are not more forceful than comparable voluntary actions or utterances and are typically not noticed because of their intensity.	0	0	2
MODERATE INTENSITY Tics are more forceful than comparable voluntary actions but are not outside the range of normal expression for comparable voluntary actions or utterances. They may call attention to the individual because of their forceful character.	0	0	3
MARKED INTENSITY Tics are more forceful than comparable voluntary actions or utterances and typically have an "exaggerated" character. Such tics frequently call attention to the individual because of their forceful and exaggerated character.	0	0	4
SEVERE INTENSITY Tics are extremely forceful and exaggerated in expression. These tics call attention to the individual and may result in risk of physical injury (accidental, provoked, or self-inflicted) because of their forceful expression.	0	0	5

COMPLEXITY

	Motor	Phonic	
NONE If present, all tics are clearly "simple" (sudden, brief, purposeless) in character.	0	0	0
BORDERLINE Some tics are not clearly "simple" in character.	0	0	1
MILD Some tics are clearly "complex" (purposive in appearance) and mimic brief "automatic" behaviors, such as grooming, syllables, or brief meaningful utterances such as "ah huh," "hi" that could be readily camouflaged.	0	0	2
MODERATE Some tics are more "complex" (more purposive and sustained in appearance) and may occur in orchestrated bouts that would be difficult to camouflage but could be rationalized or "explained" as normal behavior or speech (picking, tapping, saying "you bet" or "honey", brief echolalia).	0	0	3
MARKED Some tics are very "complex" in character and tend to occur in sustained orchestrated bouts that would be difficult to camouflage and could not be easily rationalized as normal behavior or speech because of their duration and/or their unusual, inappropriate, bizarre or obscene character (a lengthy facial contortion, touching genitals, echolalia, speech atypicalities, longer bouts of saying "what do you mean" repeatedly, or saying "fu" or "sh").	0	0	4
SEVERE Some tics involve lengthy bouts of orchestrated behavior or speech that would be impossible to camouflage or successfully rationalize as normal because of their duration and/or extremely unusual, inappropriate, bizarre or obscene character (lengthy displays or utterances often involving copropraxia, self-abusive behavior, or coprolalia).	0	0	5

INTERFERENCE

	Motor	Phonic	
NONE	0	0	0
MINIMAL When tics are present, they do not interrupt the flow of behavior or speech.	0	0	1
MILD When tics are present, they occasionally interrupt the flow of behavior or speech.	0	0	2
MODERATE When tics are present, they frequently interrupt the flow of behavior or speech.	0	0	3
MARKED When tics are present, they frequently interrupt the flow of behavior or speech, and they occasionally disrupt intended action or communication.	0	0	4
SEVERE When tics are present, they frequently disrupt intended action or communication.	0	0	5

IMPAIRMENT

NONE	0	0
MINIMAL Tics associated with subtle difficulties in self-esteem, family life, social acceptance, or school or job functioning (infrequent upset or concern about tics vis a vis the future, periodic, slight increase in family tensions because of tics, friends or acquaintances may occasionally notice or comment about tics in an upsetting way).	0	10
MILD Tics associated with minor difficulties in self-esteem, family life, social acceptance, or school or job functioning.	0	20
MODERATE Tics associated with some clear problems in self-esteem family life, social acceptance, or school or job functioning (episodes of dysphoria, periodic distress and upheaval in the family, frequent teasing by peers or episodic social avoidance, periodic interference in school or job performance because of tics).	0	30
MARKED Tics associated with major difficulties in self-esteem, family life, social acceptance, or school or job functioning.	0	40
SEVERE Tics associated with extreme difficulties in self-esteem, family life, social acceptance, or school or job functioning (severe depression with suicidal ideation, disruption of the family (separation/ divorce, residential placement), disruption of social tics - severely restricted life because of social stigma and social avoidance, removal from school or loss of job).	0	50

SCORING

	Number (0-5)	Frequency (0-5)	Intensity (0-5)	Complexity (0-5)	Interference (0-5)	Total (0-25)
Motor Tic Severity						
Vocal Tic Severity						

Total Tic Severity Score = Motor Tic Severity + Vocal Tic Severity (0-50)	
Total Yale Global Tic Severity Scale Score (Total Tic Severity Score + Impairment) (0-100)	