

Attachment 3: Adult Self Report (18 years and older)

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Public reporting burden of this collection of information is estimated to average 60 minutes, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS H21-8, Atlanta, Georgia 30333; ATTN: PRA (0920-24EG).

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

Question sources for the **adult self-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/>)
- Behavioral Risk Factor Surveillance System (BRFSS) (<https://www.cdc.gov/brfss/>)
- Current Population Survey (CPS) <https://www.census.gov/programs-surveys/cps/technical-documentation/questionnaires.html>
- 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
- National Survey on Drug Use and Health (NSDUH) <https://www.samhsa.gov/data/data-we-collect/nsduh-national-survey-drug-use-and-health>
- Youth Risk Behavior Survey https://www.cdc.gov/yrbs/media/pdf/2023/2023_YRBS_Standard_HS_Questionnaire.pdf

The survey will include two validated measures:

- Patient Health Questionnaire (PHQ-9)
- Generalized Anxiety Disorder 7-item (GAD-7)

Additionally, there will be a 2-part clinical assessment (this is included in the burden calculation):

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

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We were mindful of the benefits of using previously tested and/or approved questions for adoption in the tic surveillance 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 from our survey 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, we revised parent-report healthcare transition questions from the Longitudinal National Survey of Children’s Health to ask young adults directly about their experiences with healthcare transition. 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
<i>This survey asks questions about your mental health and emotions. If you say that you have thought about hurting yourself or have tried to do so, we may inform your doctor or clinic staff. This is to make sure you are safe and to help you get support and care.</i> <i>By filling out this survey, you agree to this process. If you have any worries or need help right away, please talk to the clinic staff.</i> <i>You do not have to complete the survey if you don't want to. If you feel uncomfortable with a question, you can leave it blank.</i>	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. If the respondent indicates they are not between 18-26, they will receive the following message: If you are under the age of 18, over the age of 26, or if you are filling this out for a child under the age of 18, please request an alternative form from the project staff.		
What is your date of birth?	Month/Day/Year	
Please answer the following questions about yourself.		
What is your 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.	HHS/OMB approved method to ask R/E questions.

	▪ Middle Eastern or North African. For example, Lebanese, Iranian, Egyptian, Syrian, Iraqi, Israeli, etc. ▪ 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.	
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B. Patient Health Questionnaire (PHQ-9)

Proposed Question	Response options	Taken From
Over the <u>last 2 weeks</u>, how often have you been bothered by any of the following problems?		PHQ-9 (validated measure)
Little interest or pleasure in doing things	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	PHQ-9
Feeling down, depressed, or hopeless	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	PHQ-9
Trouble falling or staying asleep, or sleeping too much	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	PHQ-9
Feeling tired or having little energy	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	PHQ-9
Poor appetite or overeating	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	PHQ-9
Feeling bad about yourself - or that you are a failure or have let yourself or your family down	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	PHQ-9
Trouble concentrating on things, such as reading the newspaper or watching television	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	PHQ-9

Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	PHQ-9
Thoughts that you would be better off dead or of hurting yourself in some way	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	PHQ-9
If you checked off <u>any</u> problems, how <u>difficult</u> have these problems made it for you to do your work, take care of things at home, or get along with other people?	▪ Not difficult at all ▪ Somewhat difficult ▪ Very difficult ▪ Extremely difficult	PHQ-9 [Only asked if respondent selects something other than “not at all” for any of the PHQ-9 questions].

C. Self-injury and Suicide

Question	Response Options	Taken From
During the past 12 months, how many times did you do something to purposely hurt yourself without wanting to die, such as cutting or burning yourself on purpose?	▪ 0 times ▪ 1 time ▪ 2 or 3 times ▪ 4 or 5 times ▪ 6 or more times	YRBS
The next few questions are about thoughts of suicide. At any time in the past 12 months, that is from [DATEFILL] up to and including today, did you seriously think about trying to kill yourself?	▪ Yes ▪ No	NSDUH [SUI01]
During the past 12 months, did you make any plans to kill yourself?	▪ Yes ▪ No	NSDUH [SUI02]
During the past 12 months, did you try to kill yourself?	▪ Yes ▪ No	NSDUH [SUI03]
[IF SUI03=1] During the past 12 months, did you get medical attention from a doctor or other health professional as a result of an attempt to kill yourself?	▪ Yes ▪ No	NSDUH [SUI04]
[IF SUI04=1] Did you stay in a hospital overnight or longer because you tried to kill yourself?	▪ Yes ▪ No	NSDUH [SUI05]

If you ever feel like you need to talk about mental health issues, emotional pain, or problems with alcohol or drugs, you can call or text the 988 Suicide and Crisis Lifeline at 988. Counselors are available 24/7 to listen and help you find services in your area. They can speak with you in English or Spanish. Please save this number and website: 988 (call or text) https://988lifeline.org/	NSDUH AHELP, adapted <i>In NSDUH, this information was originally only offered if YSUI01, YSUI02 or</i>
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	YSUI03=1, but we will provide for all.
[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 any other conditions you might have along with your tic disorder.

Questions and Response Options				Taken From
Have you EVER been told by a doctor or other health professional that you had:		Question B: Do you 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]	Stem is from NHIS. Follow-up is adapted for self-report from NSCH.
Any type of anxiety disorder? <i>Some common types of anxiety disorders include generalized anxiety disorder, social anxiety disorder, panic disorder, and phobias.</i>	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NHIS, follow-up questions adapted from NSCH. Removed OCD and PTSD as examples.
Any type of 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	NHIS, follow-up questions adapted from NSCH.
Autism or Autism Spectrum Disorder?	▪ Yes ▪ No	▪ Yes ▪ No	▪ Mild ▪ Moderate ▪ Severe	NSCH

<i>This includes diagnoses of Asperger's Disorder or Pervasive Developmental Disorder (PDD).</i>				
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?	▪ 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	NS-DATA, NHIS (pulled from anxiety question).
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
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.
Self-injurious behavior?	▪ 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. NSCH first asks about whether they sought care, and then about if they were told.

Have you EVER been told by a doctor or educator that you had: <i>Examples of educators are teachers and school nurses.</i>		Question B: Do you 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]	Stem is from NHIS. Follow-up is adapted for self-report from 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 you currently have:		
Allergies (such as food, drug, insect, seasonal, or other)?	☐ Yes ☐ No	NSCH

Asthma?	- Yes - No	NSCH
Autoimmune disease (such as Type 1 Diabetes, Celiac, or Juvenile Idiopathic Arthritis)?	- Yes - No	NSCH
Type 2 Diabetes?	- Yes - No	NSCH
Epilepsy or Seizure Disorder?	- Yes - No	NSCH

Question	Response Options	Taken From
Have you ever shown extreme expression of anger, often to the point of uncontrollable rage that is disproportionate to the situation at hand?	- Yes - No	Adapted from NS-DATA question on intermittent explosive disorder
[If yes to ever] Do you currently show extreme expression of anger?	- Yes - No	
[If yes to current] Would you describe it as mild, moderate or severe?	- Mild - Moderate - Severe	
Have you ever had sensory processing problems? For example, being hypersensitive (over-responsive) to certain sensations (like certain lights, sounds, touch, tastes, or smells) or hyposensitive (under-responsive) and seek out sensory input, to the point that it causes distress.	- 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.
[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 treatment for tic disorders and related conditions.

Question	Response:	Origin and notes:
The next questions ask about medications you may be taking for a tic disorder or related conditions. Related conditions include things like ADHD, OCD, anxiety, depression, behavior issues, or other mental health conditions.		
Have you 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 you first start taking medication for a tic disorder or related conditions?	Free text	NS-DATA TS_C1_2
Are you currently taking medication for a tic disorder or related conditions?	- Yes [Go to TS_C1_4]; - No [Go to TS_C3_1];	NS-DATA TS_C1_3

What medications do you 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 you take your medication for a tic disorder or related conditions?	▪ I do ▪ A parent or guardian ▪ Another family member or adult ▪ 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
Please specify the relationship of the other person who usually makes sure you take your medication for a tic disorder or related conditions:	Free text	Note: This will only be asked if selected "other" for previous question, and a space will appear in previous question. This text will not show.
The next questions ask about other treatments for a tic disorder or <u>related conditions</u>. <u>Related conditions</u> include things like ADHD, OCD, anxiety, depression, behavior issues, or other mental health conditions.		
Have you 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
Are you currently receiving comprehensive behavior intervention for tics (CBIT) or habit reversal therapy for a tic disorder?	▪ Yes ▪ No ▪ Don't know	NS-DATA TS_C3_1A
Have you 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
Are you 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 ▪ Not currently in school	NS-DATA TS_C3_2A

Have you ever received behavioral treatment based outside of school for a tic disorder or related conditions?	- Yes [GO TO TS_C3_3A] - No [GO TO TS_C3_4]; - Don't know	NS-DATA TS_C3_3
Are you currently receiving behavior treatment based outside of school for a tic disorder or related conditions?	- Yes - No - Don't know	NS-DATA TS_C3_3A
Have you ever received any other treatment for a tic disorder or related conditions?	- Yes - No [GO TO TS_C4_3]; - Don't know [GO TO TS_C4_3];	NS-DATA TS_C3_4
Please specify any other treatment you have ever received for a tic disorder or related conditions:	Free text	Note: This will only be asked if selected "YES" for previous question
Are you currently receiving any other treatment for a tic disorder or related conditions?	- Yes - No (skip next question) - Don't know (skip next question)	NS-DATA TS_C3_4A
Please specify any other treatment you are currently receiving for a tic disorder or related conditions:	Free text	Note: This will only be asked if selected "YES" for previous question
Overall, how satisfied are you with your 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
In the past year, have you received any of the following for any mental, emotional, or behavioral problem, across settings (school, doctor's office)? Select all that apply.	- Social skills training - Cognitive behavioral therapy - Counseling (for example, talk therapy or psychotherapy) - Other (please specify) - None of these [Note: REDCap programmed to not allow response of "none of these" and another response].	PLAY-MH Replaced "his/her" with "any". Each of these treatment types were asked as separate questions – propose combining with "select all that apply" response options. Omitted "parent training" from adult response options.
[If other] Please specify any other treatment you have received for any mental, emotional, or behavioral problem.	Free text	Note: This will only be asked if "Other" selected for previous question, and a box will appear in previous question, they will not see the question text here.

[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. The next questions ask about the transition from pediatric to adult health care.

Proposed Question	Response Options	Taken From
SINCE TURNING 18, have you made the transfer to a primary care provider who treats adults?	- I already saw a primary care provider who treats adults before I turned 18 → SKIP to question B22 - Yes - No – skip to B20	NSCH longitudinal survey B16 , adapted for self-report
[If yes,] How satisfied were you with the health care providers' help to transfer your care to adult health care?	- Very satisfied - Somewhat satisfied - Somewhat dissatisfied - Very dissatisfied	NSCH longitudinal survey B17 , adapted for self-report, added skip pattern
[If no to first question,] Has a doctor or other health care provider talked with you about the process of transferring to adult care?	- Yes - No	NSCH longitudinal survey B20 , adapted for self-report
Have any of your doctors or other health care providers helped with finding a new primary care provider who treats adults? <i>Examples of assistance include suggesting names of adult providers, making introductions, or sending a letter to the new provider.</i>	- Yes, and I have seen a primary care provider who treats adults - Yes, but I have not been able to see a primary care provider who treats adults - No	NSCH longitudinal survey B21 , adapted for self-report. Only one Yes option included on NSCH. We split in two.
SINCE TURNING 18, have you needed to see a mental health professional? <i>Mental health professionals include psychiatrists, psychologists, psychiatric nurses, and clinical social workers.</i>	- Yes - No – skip to B24	NSCH longitudinal survey B22 , adapted for self-report
[If yes,] Did your doctors or other health care providers help with finding mental health professionals who care for adults?	- Yes, and I have seen a mental health provider who cares for adults - Yes, but I have not been able to see a mental health provider who cares for adults - No	NSCH longitudinal survey B23 , adapted for self-report. Only one Yes option included on NSCH. We split in two.

SINCE TURNING 18, have you needed to see a specialist other than a mental health professional? <i>Examples of specialists include doctors like surgeons, heart doctors, allergy doctors, skin doctors, and others who specialize in one area of health care. Do not include dentists or other oral health care providers.</i>	▪ Yes ▪ No, skip next question	NSCH longitudinal survey B24, adapted for self-report
Did your doctors or other health care providers help with finding specialists who care for adults (other than mental health professionals)?	▪ Yes, and I have seen a specialist who cares for adults ▪ Yes, but I have not been able to see a specialist who cares for adults ▪ No	NSCH longitudinal survey B25, adapted for self-report. Only one Yes option included on NSCH. We split in two.
SINCE TURNING 18, did you need to find a new health professional for care related to your tic disorder?	▪ Yes ▪ No, skip to New3	New question, based on NSCH longitudinal survey questions (New1)
Did your doctors or other health care providers help with finding a health professional who cares for adults with tic disorders? <i>Examples of assistance include suggesting names of adult providers, making introductions, or sending a letter to the new provider.</i>	▪ Yes, and I have seen a health professional who cares for adults with tic disorders ▪ Yes, but I have not been able to see a health professional who cares for adults with tic disorders ▪ No	New question, based on NSCH longitudinal survey questions (New2)
SINCE TURNING 18, have you had any of the following challenges in finding a health professional who treats tic disorders in adults? Select all that apply. Providers in my area that treat tic disorders in adults...	▪ are not accepting new patients ▪ do not take my health insurance ▪ do not have appointments in the next 6 months ▪ do not have appointments that fit my schedule ▪ do not offer in-person appointments ▪ do not telehealth/virtual appointments ▪ there are no providers that treat tic disorders in adults in my area ▪ I have had a different problem	New question, based on NSCH longitudinal survey questions (New3)

	▪ I haven't had any problems finding a health professional who treats tic disorders in adults	
[If answered "I have had a different problem" in previous question] What other challenges (not listed above) have you faced in finding a health professional who treats tic disorders in adults?	Free Text (word limit: 125 words)	New question, based on NSCH longitudinal survey questions (New4)
[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.		

G. The next questions ask about employment and use of health care services.

Question	Responses	From
LAST WEEK, did you work for pay at a job or business?	- Yes [go to EMPHOURS_A] - No [go to EMPNOWRK_A]	NHIS EMPLASTWK_A
Did you have a job or business LAST WEEK, but were temporarily absent due to illness, vacation, family or maternity leave, or some other reason?	- Yes [go to EMPHOURS_A] - No [go to EMPWHYNOT_A]	NHIS EMPNOWRK_A
What is the MAIN reason you were not working for pay at a job or business last week?	- Unemployed, laid off, looking for work - Seasonal/contract work - Retired - Unable to work for health reasons/disabled - Taking care of house or family - Going to school - Working at a family-owned job or business not for pay [go to EMPHOURS_A] - Other	NHIS EMPWHYNOT_A
When was the last time you worked for pay at a job or business, even if only for a few days?	- Within the past 12 months [if EMPWHYNOT_A= "Seasonal/contract work" [go to EMPHOURS_A] else [go to Next Section]] 1-5 years ago [go to Next Section – about out of pocket expenses] - Over 5 years ago [go to Next Section about out of pocket expenses] - Never worked [go to Next Section about out of pocket expenses]	NHIS EMPWHENWRK_A
How many hours per week do you USUALLY work in total at ALL jobs or businesses?	Free text [001-168 range of values]	NHIS EMPHOURS_A
[If previous question is missing] When you work do you USUALLY work 35 hours or more per week in total at ALL jobs or businesses?	- Yes - No	NHIS EMPFULLTIM_A
During the past 12 months, about how many days of work did you miss because you had an illness, injury, or disability? Do not include family or paternity/maternity leave.	Free text [000-365 Range of values]	NHIS EMPDAYMISS_A
Last year, how much was paid out-of-pocket for your OWN medical care, such as copays for doctor and dentist visits, diagnostic tests, prescription	\$0 (No medical or health-related expenses) \$1-\$249 \$250-\$499 \$500-\$999	CPS (ASEC); response options from NSCH

medicine, glasses and contacts, and medical supplies? <i>Include any amount paid out-of-pocket on your behalf by anyone in this household.</i>	▪ \$1,000-\$5,000 ▪ More than \$5,000	
Last year, how much was paid out-of-pocket for your non-prescription healthcare products such as vitamins, allergy and cold medicine, pain relievers, quit smoking aids, AND anything else not yet reported?] <i>Include any amount paid out-of-pocket on your behalf by anyone in this household.</i>	▪ \$0 (No medical or health-related expenses) ▪ \$1-\$249 ▪ \$250-\$499 ▪ \$500-\$999 ▪ \$1,000-\$5,000 ▪ More than \$5,000	CPS (ASEC) ; response options from NSCH
Last year, how much was paid out-of-pocket for your OWN mental health care, including copays for doctor visits, prescription medicine, and therapy or counseling? Include any amount paid out-of-pocket on your behalf by anyone in this household.	▪ \$0 (No medical or health-related expenses) ▪ \$1-\$249 ▪ \$250-\$499 ▪ \$500-\$999 ▪ \$1,000-\$5,000 ▪ More than \$5,000	Adapted from CPS questions above; response options from NSCH
During the past 12 months, have you DELAYED getting counseling or therapy from a mental health professional because of the cost?	▪ Yes ▪ No	NHIS
During the past 12 months, was there any time when you needed counseling or therapy from a mental health professional, but DID NOT GET IT because of the cost?	▪ Yes ▪ No	NHIS
During the past 12 months, have you DELAYED getting care from a mental health professional because you couldn't get an appointment?	▪ Yes ▪ No	Adapted from NHIS questions above
If yes, how long was the delay?	▪ Less than 3 months ▪ 3-6 months ▪ 7-12 months ▪ More than 12 months	New question
The next questions are about your medical bills. Include bills for doctors, dentists, hospitals, therapists, medication, equipment, and nursing home or home care.		NHIS
In the past 12 months, did you have problems paying or were unable to pay any medical bills?	▪ Yes ▪ No	NHIS
Do you currently have any medical bills that you are unable to pay at all?	▪ Yes ▪ No	NHIS
If you get sick or have an accident, how worried are you that you will be able to pay your medical bills? Are you very	▪ Very worried ▪ Somewhat worried ▪ Not at all worried	NHIS

worried, somewhat worried, or not at all worried?		
During the past 12 months, have you DELAYED getting medical care because of the cost?	- Yes - No	NHIS RXDL12M_A
During the past 12 months, was there any time when you needed medical care, but DID NOT GET IT because of the cost?	- Yes - No	NHIS RXDG12M_A
At any time in the past 12 months, did you take prescription medication?	- Yes - No [skip next 3 questions]	NHIS
During the past 12 months, were any of the following true for you?		NHIS
You skipped medication doses to save money.	- Yes - No	NHIS RXSK12M_A
You took less medication to save money.	- Yes - No	NHIS RXLS12M_A
You DELAYED filling a prescription to save money.	- Yes - No	NHIS RXDL12M_A
During the past 12 months, was there any time when you needed prescription medication, but DID NOT GET IT because of the cost?	- Yes - No	NHIS RXDG12M_A (asked of all)
During the past 12 months, how many times have you gone to a hospital emergency room about your health?	Open ended (restrict to 0-365)	NHIS
During the past 12 months, have you been hospitalized overnight?	- Yes - No	NHIS
[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.		

H. Additional Questions About You

Proposed Question	Response options	Taken From
Which of the following best represents how you think of yourself?	- Gay (lesbian or gay) - Straight, this is not gay (or lesbian or gay) - Bisexual - Something else - I don't know the answer	HHS/OMB approved question
What is your sex?	- Male - Female	HHS/OMB approved question

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
Are you now married, living with a partner together as an unmarried couple, or neither?	▪ Married ▪ Living with a partner together as an unmarried couple ▪ Neither	NHIS
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
Are you covered by any kind of health insurance or some other kind of health care plan?	▪ Yes ▪ No [skip next 3 questions]	NHIS
[If yes to having health insurance] What kinds of health insurance or health care coverage do you 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	NHIS [Note: REDCap programmed to not allow response of "none of these" and another response].

	(CHAMPUS) / VA health care / CHAMP-VA ▪ Indian Health Service ▪ State-sponsored health plan ▪ Other government program ▪ No coverage of any type	
[If yes to having health insurance] Health insurance plans are usually obtained in one person's name even if other family members are covered by that plan. That person is called the policyholder. Are you the policyholder for your health insurance plan ?	▪ Yes [skip next question] ▪ No	NHIS
[If no to being the policy holder] How are you related to the policyholder for your health insurance ? Are you the policyholder's child, spouse, former spouse, or are you related in some other way?	▪ Child ▪ Spouse ▪ Former spouse ▪ Some other relationship	NHIS
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)	
Please specify other place (not US state) you live	Free text	For those who answer "Other" for state
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 [Numeric]	NSCH
What is your best estimate of your total family income from all sources, before taxes, in the last year?	▪ <\$15,000 ▪ \$15,000-\$24,999 ▪ \$25,000-49,999 ▪ \$50,000-74,999 ▪ \$75,000-99,999 ▪ \$100,000-149,999	NHIS Slightly different response categories than NHIS

	▪ \$150,000-199,999 ▪ \$200,000 or higher	
Some people who are deaf or have serious difficulty hearing use assistive devices to communicate by phone. Are you deaf or do you have serious difficulty hearing?	▪ Yes ▪ No	BRFSS 2022 CDIS.01
Are you blind or do you have serious difficulty seeing, even when wearing glasses?	▪ Yes ▪ No	BRFSS 2022 CDIS.02
Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?	▪ Yes ▪ No	BRFSS 2022 CDIS.03
Do you have serious difficulty walking or climbing stairs?	▪ Yes ▪ No	BRFSS 2022 CDIS.04
Do you have difficulty dressing or bathing?	▪ Yes ▪ No	BRFSS 2022 CDIS.05
Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?	▪ Yes ▪ No	BRFSS 2022 CDIS.06
[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.		

I. The final questions ask about problems that may have bothered you over the past 2 weeks, followed by two additional questions about you.

Question	Response Options	Taken From
Over the last 2 weeks, how often have you been bothered by the following problems?		GAD-7
Feeling nervous, anxious or on edge	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	GAD-7
Not being able to stop or control worrying	▪ Not at all ▪ Several days ▪ More than half the days ▪ Nearly every day	GAD-7
Worrying too much about different things	▪ Not at all ▪ Several days ▪ More than half the days	GAD-7

	Nearly every day	
Trouble relaxing	- Not at all - Several days - More than half the days - Nearly every day	GAD-7
Being so restless that it is hard to sit still	- Not at all - Several days - More than half the days - Nearly every day	GAD-7
Becoming easily annoyed or irritable	- Not at all - Several days - More than half the days - Nearly every day	GAD-7
Feeling afraid as if something awful might happen	- Not at all - Several days - More than half the days - Nearly every day	GAD-7
If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	- Not difficult at all - Somewhat difficult - Very difficult - Extremely difficult	GAD-7 [only asked of those who endorse more than “not at all” in this section]

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.

J. Clinical Assessments

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

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)	