#### 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) <a href="https://www.census.gov/content/dam/Census/programs-surveys/nsch/tech-documentation/questionnaires/2023/2023">https://www.census.gov/content/dam/Census/programs-surveys/nsch/tech-documentation/questionnaires/2023/2023</a> NSCH-T3 FINAL.pdf
- National Health Interview Survey (NHIS) (<a href="https://www.cdc.gov/nchs/nhis/">https://www.cdc.gov/nchs/nhis/</a>)
- Behavioral Risk Factor Surveillance System (BRFSS) (https://www.cdc.gov/brfss/)
- Current Population Survey (CPS) <a href="https://www.census.gov/programs-surveys/cps/technical-documentation/questionnaires.html">https://www.census.gov/programs-surveys/cps/technical-documentation/questionnaires.html</a>
- 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)
   <a href="https://ftp.cdc.gov/pub/Health\_Statistics/NCHS/slaits/ns\_data/NS\_DATA\_Questionnaire.pdf">https://ftp.cdc.gov/pub/Health\_Statistics/NCHS/slaits/ns\_data/NS\_DATA\_Questionnaire.pdf</a>
- National Survey on Drug Use and Health (NSDUH) <a href="https://www.samhsa.gov/data/data-we-collect/nsduh-national-survey-drug-use-and-health">https://www.samhsa.gov/data/data-we-collect/nsduh-national-survey-drug-use-and-health</a>
- 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
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	Revised from a previous project.
inform your doctor or clinic staff. This is to make sure you are safe and to help you get support and care.	
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.  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.	

		1				
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 r	notifications (if they are completing the w	rong 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 respond	ent. If the respondent indicates				
they are not between 18-26, they will r	eceive the following message: <mark>If you are u</mark>	inder the <b>age of 18, over the</b>				
age of 26, or if you are filling this out fo	r a child under the age of 18, please requ	uest 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?  • American Indian or Alaska Native HHS/OMB approved method						

#### What is your race and/or ethnicity? HHS/OMB approved method American Indian or Alaska Native. Select all that apply. For example, Navajo Nation, to ask R/E questions. 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.
■ 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.

#### B. Patient Health Questionnaire (PHQ-9)

Proposed Question	Response options	Taken From
Over the <u>last 2 weeks</u> , how often he following problems?	PHQ-9 (validated measure)	
Little interest or pleasure in doing things	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	PHQ-9
Feeling down, depressed, or hopeless	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	PHQ-9
Trouble falling or staying asleep, or sleeping too much	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	PHQ-9
Feeling tired or having little energy	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	PHQ-9
Poor appetite or overeating	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	PHQ-9
Feeling bad about yourself - or that you are a failure or have let yourself or your family down	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	PHQ-9
Trouble concentrating on things, such as reading the newspaper or watching television	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	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	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	PHQ-9
Thoughts that you would be better off dead or of hurting yourself in some way  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?	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> <li>Not difficult at all</li> <li>Somewhat difficult</li> <li>Very difficult</li> <li>Extremely difficult</li> </ul>	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?	<ul> <li>0 times</li> <li>1 time</li> <li>2 or 3 times</li> <li>4 or 5 times</li> <li>6 or more times</li> </ul>	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?	<ul><li>Yes</li><li>No</li></ul>	NSDUH [SUI02]
During the past 12 months, did you <b>try</b> 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	NSDUH <b>AHELP</b> ,
with alcohol or drugs, you can call or text the 988 Suicide and Crisis Lifeline at 988.	adapted
Counselors are available 24/7 to listen and help you find services in your area. They can	
speak with you in English or Spanish.	In NSDUH, this
	information was
Please save this number and website:	originally only
988 (call or text)	offered if YSUI01,
https://988lifeline.org/	YSUI02 or

	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 next page. If you intentionally skipped the question(s), you can go to the next	s) before going to the

#### 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 on the alth professional that you had:	othe	r	yo the [Sk the res pre wil	restion B: Do  u currently have e condition?  kip logic: Only ose who spond "Yes" to evious question li be asked restion B]	de mi or [Sk tho res to wil	restion C:  buld you  scribe it as  ld, moderate severe?  sip logic: Only be who spond "Yes" question B  ll be asked restion C]	Stem is from NHIS. Follow-up is adapted for self- report from NSCH.
Any type of anxiety disorder?  Some common types of anxiety disorders include generalized anxiety disorder, social anxiety disorder, panic disorder, and phobias.	•	Yes No	•	Yes No	•	Mild Moderate Severe	NHIS, follow-up questions adapted from NSCH. Removed OCD and PTSD as examples.
Any type of depression?  Some common types of depression include major depression (or major depressive disorder), bipolar depression, dysthymia, post-partum depression, and seasonal affective disorder.	•	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

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This includes diagnoses of Asperger's							
Disorder or Pervasive Developmental							
Disorder (PDD).							
Attention Deficit Disorder or Attention-	-	Yes	•	Yes	•	Mild	NSCH
Deficit/Hyperactivity Disorder, that is,	•	No	•	No	•	Moderate	
ADD or ADHD?					•	Severe	
Obsessive-compulsive disorder or OCD?	-	Yes	•	Yes	•	Mild	NS-DATA, NHIS
·	-	No	-	No	•	Moderate	(pulled from
					•	Severe	anxiety question).
Post-traumatic stress disorder or PTSD?	-	Yes	-	Yes	•	Mild	NS-DATA, NHIS
	•	No		No		Moderate	(pulled from
						Severe	anxiety question).
Substance use disorder?	-	Yes	-	Yes	•	Mild	NS-DATA
Substance use disorder.		No		No		Moderate	No Branc
Substance abuse is the frequent use of		110		140	-	Severe	
substances such as drugs that can be					-	Jevere	
physically dangerous and can potentially							
. , , ,							
lead to legal problems and frequent							
social or interpersonal problems.							
Frequent or severe headaches, including	•	Yes	•	Yes	•	Mild	NSCH
migraine?	•	No	•	No	•	Moderate	
					•	Severe	
A 1 11 2		.,				8.411.1	NC DATA
A sleep disorder?	•	Yes	•	Yes	•	Mild	NS-DATA
	•	No	•	No	•	Moderate	
Examples of sleep disorders include sleep					•	Severe	
apnea, insomnia, and narcolepsy.							
Eating disorder?	-	Yes	-	Yes	•	Mild	SEED follow-up
	•	No	•	No	•	Moderate	survey, with
					•	Severe	addition of severity
							question.
Self-injurious behavior?	-	Yes	•	Yes	•	Mild	SEED follow-up
	•	No	•	No	•	Moderate	survey, with
					•	Severe	addition of severity
							question.
A concussion or brain injury?	-	Yes					Adapted from
		No					NSCH. NSCH first
A concussion or brain injury is when a							asks about whether
blow or jolt to the head causes							
problems such as headaches,							they sought care,
dizziness, being dazed or confused,							and then about if
difficulty remembering or							they were told.
, ,							
concentrating, vomiting, blurred							
vision, changes in mood or behavior,							
or being knocked out.							

Questions and Response	e Options	Taken From

doctor <u>or educator</u> tha	Have you EVER been told by a doctor or educator that you had:  Examples of educators are teachers and school nurses.  [Skip logic: Only the who respond "Yes" previous question who had asked Question I		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?	<ul><li>Yes</li><li>No</li></ul>	• Yes • No	<ul><li>Mild</li><li>Moderate</li><li>Severe</li></ul>	NSCH
Developmental delay?	■ Yes ■ No	■ Yes ■ No	<ul><li>Mild</li><li>Moderate</li><li>Severe</li></ul>	NSCH
Intellectual disability (formerly known as mental retardation)?	■ Yes ■ No	■ Yes ■ No	<ul><li>Mild</li><li>Moderate</li><li>Severe</li></ul>	NSCH
Speech disorder?	■ Yes ■ No	■ Yes ■ No	<ul><li>Mild</li><li>Moderate</li><li>Severe</li></ul>	NSCH  Adapted: split out into two questions (speech and language separate)
Language disorder?	■ Yes ■ No	■ Yes ■ No	<ul><li>Mild</li><li>Moderate</li><li>Severe</li></ul>	NSCH  Adapted: split out into two questions (speech and language separate)
Learning disability?	■ Yes ■ No	■ Yes ■ No	<ul><li>Mild</li><li>Moderate</li><li>Severe</li></ul>	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	NSCH
	■ No	

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

Question	Response Options	Taken From
Have you ever shown extreme expression of anger, often	■ Yes	Adapted from NS-DATA
to the point of uncontrollable rage that is	■ No	question on intermittent
disproportionate to the situation at hand?		explosive disorder
[If yes to ever} Do you currently show extreme expression	■ Yes	
of anger?	■ No	
[If yes to current] Would you describe it as mild,	<ul><li>Mild</li></ul>	
moderate or severe?	<ul><li>Moderate</li></ul>	
	<ul><li>Severe</li></ul>	
Have you ever had sensory processing problems?	■ Yes	Edited from SEED question
	■ No	asking about sensory integration
For example, being hypersensitive (over-responsive) to		disorder, which isn't recognized
certain sensations (like certain lights, sounds, touch,		as a disorder, so we are
tastes, or smells) or hyposensitive (under-responsive) and		rephrasing as problems the
seek out sensory input, to the point that it causes distress.		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 ma related conditions.	y be taking for <mark>a tic disorder or</mark>	
<u>Related conditions</u> include things like ADHD, OCD, or other mental health conditions.	anxiety, depression, behavior issues,	
Have you <b>ever</b> taken medication for a tic disorder or related conditions?	<ul><li>Yes [Go to TS_C1_2]</li><li>No [Go to TS_C3_1]</li></ul>	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?	<ul> <li>Yes [Go to TS_C1_4];</li> <li>No [Go to TS_C3_1];</li> </ul>	NS-DATA TS_C1_3

What medications do you currently take for a tic	Free text	NS-DATA TS_C1_4_NEW
disorder or related conditions?		
		Original question had
Please list all.		multiple choice/select all
		response options (phone
		survey).
Who usually makes sure you take your	I do	NS-DATA TS_C2_1
medication for a tic disorder or related conditions?	<ul><li>A parent or guardian</li><li>Another family member or</li></ul>	Original recognitions
conditions:	adult .	Original response options:
	<ul> <li>Other person (please specify</li> </ul>	(1) A PARENT OR
	relationship of other person)	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	Free text	Note: This will only be
person who usually makes sure you take your		asked if selected "other"
medication for a tic disorder or related		for previous question, and
conditions:		a space will appear in previous question. This
		text will not show.
The next questions ask about other treatments fo	r a tic disorder or related	
conditions.	<del></del> -	
Related conditions include things like ADHD, OCD,	anxiety, depression, behavior issues,	
or other mental health conditions.		
Have you ever received comprehensive	<ul><li>Yes [go to TS_C3_1A;]</li></ul>	NS-DATA TS_C3_1
behavioral intervention for tics (CBIT) or habit	<ul> <li>No [go to TS_C3_2];</li> </ul>	
reversal therapy for <mark>a tic disorder</mark> ?	■ Don't know [go to	
Are you currently receiving comprehensive	TS_C3_2];  • Yes	NS-DATA TS C3 1A
behavior intervention for tics (CBIT) or habit	■ No	N3-DAIA 13_C3_1A
reversal therapy for a tic disorder?	■ Don't know	
Have you ever received school-based behavioral	<ul> <li>Yes [GO TO TS_C3_2A];</li> </ul>	NS-DATA TS_C3_2
treatment, support, or accommodation for a tic	■ No [GO TO TS_C3_3];	
disorder or related conditions?	■ Don't know [GO TO	
	TS_C3_3]	
Do not include CBIT or habit reversal therapy.	- W.	NC DATA TO CO CA
Are you currently receiving school-based	<ul><li>Yes</li><li>No</li></ul>	NS-DATA TS_C3_2A
behavioral treatment, support, or accommodation for a tic disorder or related	■ No ■ Don't know	
conditions?	<ul> <li>Not currently in school</li> </ul>	
	<u> </u>	
Do not include CBIT or habit reversal therapy.		

	1	T
Have you ever received behavioral treatment based outside of school for a tic disorder or related conditions?	<ul><li>Yes [GO TO TS_C3_3A]</li><li>No [GO TO TS_C3_4];</li><li>Don't know</li></ul>	NS-DATA TS_C3_3
Are you currently receiving behavior treatment based outside of school for a tic disorder or related conditions?	<ul><li>Yes</li><li>No</li><li>Don't know</li></ul>	NS-DATA TS_C3_3A
Have you ever received any other treatment for a tic disorder or related conditions?	<ul> <li>Yes</li> <li>No [GO TO TS_C4_3];</li> <li>Don't know [GO TO TS_C4_3];</li> </ul>	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?	<ul> <li>Yes</li> <li>No (skip next question)</li> <li>Don't know (skip next question)</li> </ul>	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?	<ul> <li>Very satisfied;</li> <li>Somewhat satisfied;</li> <li>Somewhat dissatisfied;</li> <li>Very dissatisfied;</li> </ul>	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.	<ul> <li>Social skills training</li> <li>Cognitive behavioral therapy</li> <li>Counseling (for example, talk therapy or psychotherapy)</li> <li>Other (please specify)</li> <li>None of these</li> <li>[Note: REDCap programmed to not allow response of "none of these" and another response].</li> </ul>	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
[If other] Please specify any other treatment you have received for any mental, emotional, or behavioral problem.	■ Free text	options.  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?	<ul> <li>I already saw a primary care provider who treats adults before I turned 18</li> <li>→ SKIP to question B22</li> <li>Yes</li> <li>No – skip to B20</li> </ul>	NSCH longitudinal survey <mark>B16</mark> , adapted for self-report
[If yes,] How satisfied were you with the health care providers' help to transfer your care to adult health care?	<ul><li>Very satisfied</li><li>Somewhat satisfied</li><li>Somewhat dissatisfied</li><li>Very dissatisfied</li></ul>	NSCH longitudinal survey <mark>B17</mark> , 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?	<ul><li>Yes</li><li>No</li></ul>	NSCH longitudinal survey <b>B20</b> , 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?  Examples of assistance include suggesting names of adult providers, making introductions, or sending a letter to the new provider.	<ul> <li>Yes, and I have seen a primary care provider who treats adults</li> <li>Yes, but I have not been able to see a primary care provider who treats adults</li> <li>No</li> </ul>	NSCH longitudinal survey <b>B21</b> , 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?  Mental health professionals include psychiatrists, psychologists, psychiatric nurses, and clinical social workers.	<ul><li>Yes</li><li>No – skip to B24</li></ul>	NSCH longitudinal survey <b>B22</b> , adapted for self-report
[If yes,] Did your doctors or other health care providers help with finding mental health professionals who care for adults?	<ul> <li>Yes, and I have seen a mental health provider who cares for adults</li> <li>Yes, but I have not been able to see a mental health provider who cares for adults</li> <li>No</li> </ul>	NSCH longitudinal survey <b>B23</b> , 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?  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.  Did your doctors or other health care providers help with finding specialists who care for adults (other than mental health professionals)?	<ul> <li>Yes</li> <li>No, skip next question</li> <li>Yes, and I have seen a specialist who cares for adults</li> <li>Yes, but I have not been</li> </ul>	NSCH longitudinal survey <b>B24</b> , adapted for self-report  NSCH longitudinal survey <b>B2</b> 5, adapted for self-report. Only one Yes option
SINCE TURNING 18, did you need to find a new health professional for care related to your tic disorder?	able to see a specialist who cares for adults  No  Yes  No, skip to New3	included on NSCH. We split in two.  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?  Examples of assistance include suggesting names of adult providers, making introductions, or sending a letter to the new provider.	<ul> <li>Yes, and I have seen a health professional who cares for adults with tic disorders</li> <li>Yes, but I have not been able to see a health professional who cares for adults with tic disorders</li> <li>No</li> </ul>	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	<ul> <li>are not accepting new patients</li> <li>do not take my health insurance</li> <li>do not have appointments in the next 6 months</li> <li>do not have appointments that fit my schedule</li> <li>do not offer in-person appointments</li> <li>do not telehealth/virtual appointments</li> <li>there are no providers that treat tic disorders in adults in my area</li> <li>I have had a different problem</li> </ul>	New question, based on NSCH longitudinal survey questions (New3)

	<ul> <li>I haven't had any problems finding a health professional who treats tic disorders in adults</li> </ul>	
[If answered "I have had a different problem" in	Free Text (word limit: 125	New question, based
previous question] What other challenges (not listed	words)	on NSCH longitudinal
above) have you faced in finding a health professional		survey questions
who treats tic disorders in adults?		(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?	<ul><li>Yes [go to EMPHOURS_A]</li><li>No [go to EMPNOWRK_A]</li></ul>	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?	<ul><li>Yes [go to EMPHOURS_A]</li><li>No [go to EMPWHYNOT_A]</li></ul>	NHIS EMPNOWRK_A
What is the MAIN reason you were not working for pay at a job or business last week?	<ul> <li>Unemployed, laid off, looking for work</li> <li>Seasonal/contract work</li> <li>Retired</li> <li>Unable to work for health reasons/disabled</li> <li>Taking care of house or family</li> <li>Going to school</li> <li>Working at a family-owned job or business not for pay [go to EMPHOURS_A]</li> <li>Other</li> </ul>	NHIS EMPWHYNOT_A
When was the last time you worked for pay at a job or business, even if only for a few days?	<ul> <li>Within the past 12 months [if EMPWHYNOT_A= "Seasonal/contract work" [go to EMPHOURS_A] else [go to Next Section]]</li> <li>1-5 years ago [go to Next Section – about out of pocket expenses]</li> <li>Over 5 years ago [go to Next Section about out of pocket expenses]</li> <li>Never worked [go to Next Section about out of pocket expenses]</li> </ul>	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 <b>medical care</b> , such as copays for doctor and dentist visits, diagnostic tests, prescription	<ul> <li>\$0 (No medical or health-related expenses)</li> <li>\$1-\$249</li> <li>\$250-\$499</li> <li>\$500-\$999</li> </ul>	CPS (ASEC); response options from NSCH

medicine, glasses and contacts, and	<b>\$1,000-\$5,000</b>	
medical supplies?	More than \$5,000	
Include any amount paid out-of-pocket		
on your behalf by anyone in this		
household.		
Last year, how much was paid out-of-	\$0 (No medical or health-related expenses)	CPS (ASEC) ; response
pocket for your <b>non-prescription</b>	<b>\$1-\$249</b>	options from NSCH
healthcare products such as vitamins,	<b>\$250-\$499</b>	
allergy and cold medicine, pain	<b>■</b> \$500-\$999	
relievers, quit smoking aids, AND	<b>\$1,000-\$5,000</b>	
anything else not yet reported?]	<ul><li>More than \$5,000</li></ul>	
Include any amount paid out-of-pocket on		
your behalf by anyone in this household.	42 (1)	
Last year, how much was paid out-of-	\$0 (No medical or health-related expenses)	Adapted from CPS
pocket for your OWN mental health	\$1-\$249	questions above;
care, including copays for doctor visits,	\$250-\$499	response options
prescription medicine, and therapy or	\$500-\$999 - \$1,000 \$5,000	from NSCH
counseling? Include any amount paid out-of-pocket on	\$1,000-\$5,000	
your behalf by anyone in this household.	<ul><li>More than \$5,000</li></ul>	
During the past 12 months, have you	■ Yes	NHIS
DELAYED getting counseling or therapy	■ No	141113
from a mental health professional because		
of the cost?		
During the past 12 months, was there any	■ Yes	NHIS
time when you needed counseling or	■ No	
therapy from a mental health professional, but DID NOT GET IT because of the cost?		
During the past 12 months, have you	■ Yes	Adapted from NHIS
DELAYED getting care from a mental health	■ No	questions above
professional because you couldn't get an	- 140	questions above
appointment?		
If yes, how long was the delay?	<ul><li>Less than 3 months</li></ul>	New question
	<ul><li>3-6 months</li></ul>	
	<ul><li>7-12 months</li></ul>	
	<ul><li>More than 12 months</li></ul>	
	cal bills. Include bills for doctors, dentists,	NHIS
hospitals, therapists, medication, equip		
In the past 12 months, did you have	■ Yes	NHIS
problems paying or were unable to pay	■ No	
any medical bills?		
Do you currently have any medical bills	■ Yes	NHIS
that you are unable to pay at all?	■ No	
	 	Auto
If you get sick or have an accident, how	Very worried	NHIS
worried are you that you will be able to	Somewhat worried	
pay your medical bills? Are you very	Not at all worried	

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

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

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#### **H.** Additional Questions About You

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

What is the HIGHEST level of school you have completed or the highest degree you have received?	<ul> <li>Never attended/kindergarten only</li> <li>Grade 1-11</li> <li>12th grade, no diploma</li> <li>GED or equivalent</li> <li>High school graduate</li> <li>Some college, no degree</li> <li>Associate degree: occupational, technical, or vocational program</li> <li>Associate degree: academic program</li> <li>Bachelor's degree (Example: BA, AB, BS, BBA)</li> <li>Master's degree (Example: MA, MS, MEng, MEd, MBA)</li> <li>Professional school degree (Example: MD, DDS, DVM, JD)</li> <li>Doctoral degree (Example: PhD, EdD)</li> </ul>	NHIS HHC.0350.00.1
Are you now married, living with a partner together as an unmarried couple, or neither?	<ul> <li>Married</li> <li>Living with a partner together as an unmarried couple</li> </ul>	NHIS
The next questions are about health insurance. Include obtained through employment or purchased directly programs like Medicare, Medicaid, and the Children's that provide medical care or help pay medical bills.  Are you covered by any kind of health insurance or some other kind of health care plan?	as well as government s Health Insurance Program  • Yes	NHIS NHIS
[If yes to having health insurance] What kinds of health insurance or health care coverage do you have? Is itPrivate 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 statesponsored health plan, or another government program?  Select all that apply.	<ul> <li>No [skip next 3 questions]</li> <li>Private health insurance</li> <li>Medicare</li> <li>Medigap</li> <li>Medicaid</li> <li>Children's Health Insurance Program (CHIP)</li> <li>Military related health care: TRICARE</li> </ul>	NHIS  [Note: REDCap programmed to not allow response of "none of these" and another response].

[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?	(CHAMPUS) / VA health care / CHAMP-VA Indian Health Service State-sponsored health plan Other government program No coverage of any type 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?	<ul><li>Child</li><li>Spouse</li><li>Former spouse</li><li>Some other relationship</li></ul>	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	

		I
	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	Free Text [Numeric]	NSCH
address? 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.		
What is your best estimate of your total family	<\$15,000	NHIS
income from all sources, before taxes, in the last	<b>\$15,000-\$24,999</b>	
year?	\$25,000-49,999	Slightly different
<b>'</b>	<b>\$50,000-74,999</b>	response categories than
	<b>\$75,000-99,999</b>	NHIS
	<b>\$100,000-149,999</b>	· · · · ·
	<del>γ100,000 143,333</del>	l .

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

[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.

## 1. 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 bor problems?	Over the last 2 weeks, how often have you been bothered by the following problems?	
Feeling nervous, anxious or on edge	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	GAD-7
Not being able to stop or control worrying	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	GAD-7
Worrying too much about different things	<ul><li>Not at all</li><li>Several days</li><li>More than half the days</li></ul>	GAD-7

	■ Nearly every day	
Trouble relaxing	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	GAD-7
Being so restless that it is hard to sit still	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	GAD-7
Becoming easily annoyed or irritable	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	GAD-7
Feeling afraid as if something awful might happen	<ul> <li>Not at all</li> <li>Several days</li> <li>More than half the days</li> <li>Nearly every day</li> </ul>	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?	<ul> <li>Not difficult at all</li> <li>Somewhat difficult</li> <li>Very difficult</li> <li>Extremely difficult</li> </ul>	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	New
		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.	
If you are interested in receiving project updates in	•	Free text	New
the future, please enter your email address.			
You may decline to be re-contacted now or at any			
time in the future.			
[If the respondent skipped any questions in this section	on, t	hey will receive the followir	ng 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 followi	ng information to the responder	nt before asking
the questions.		
This survey asks about mental health and emotional well-being. I	f you answer that you have had	<mark>suicidal</mark>
thoughts or behaviors, or purposely tried to hurt yourself, we may	-	nic staff. This
would be to ensure your safety and provide you with support and	care.	
By completing this survey, you accept and consent to this protoco	ol. If vou have concerns or need	l immediate
help, please tell the clinic staff.		
1) In the past few weeks, have you wished you were dead?	■ Yes	ASQ
	■ No	
	<ul> <li>Refused to answer</li> </ul>	
2) In the past few weeks, have you felt that you or your family	■ Yes	ASQ
would be better off if you were dead?	■ No	
	<ul><li>Refused to answer</li></ul>	
3) In the past week, have you been having thoughts about	■ Yes	ASQ
killing yourself?	■ No	
	<ul> <li>Refused to answer</li> </ul>	
4) Have you ever tried to kill yourself?	<ul><li>Yes</li></ul>	ASQ
	■ No	
	<ul> <li>Refused to answer</li> </ul>	
[If yes to 4,]	Free text	ASQ
4a) How?		
4b) When?		
The patient answered "No" to questions 1 through 4; therefore,	<ul><li>Ask question #5</li></ul>	Incorporated
screening is complete, and it is not necessary to ask question	<ul><li>Finish the ASQ</li></ul>	from ASQ
#5. No intervention is necessary; however, clinical judgment		instructions,
can always override a negative screen.		within skip
		pattern. ASQ
Do you want to ask the patient question #5 (Are you having		instructions
thoughts of killing yourself right now?) or finish the ASQ?		included
		below.
[If "Yes" or "Refused" to any of the above (Q1-Q4)] This patient is	■ Yes	ASQ
considered a positive screen. Ask question #5 to assess acuity.	■ No	
5) Are you having thoughts of killing yourself right now?		

[If yes to Q5]	Open ended	ASQ
5b) Please describe:		

[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), <a href="https://988lifeline.org/">https://988lifeline.org/</a> (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/

nups://988ureurie.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	ASQ
for reference.		
If patient answers "No" to all questions 1 through 4, screeni	ng is complete (not necessary to	
ask question #5). No intervention is necessary (*Note: Clinic	cal judgment can always override a	ı
negative screen).		
If patient answers "Yes" to any of questions 1 through 4, or re	efuses to answer, they are	
considered a positive screen. Ask question #5 to assess acu	uity.	
"Yes" to question #5 = acute positive screen (imminent ri	sk identified)	
Patient requires a STAT safety/full mental health evaluation. evaluated for safety.	Patient cannot leave until	
Keep patient in sight. Remove all dangerous objects from roresponsible for patient's care.	om. Alert physician or clinician	
"No" to question #5 (but "Yes" or "Refused" to one of que	estions 1-4) = non-acute positive	
screen (potential risk identified)	-	
Patient requires a brief suicide safety assessment to determ	nine if a full mental health	
evaluation is needed. If a patient (or parent/guardian) refuse	es the brief assessment, this should	t

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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	

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

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  $(\mathbf{x})$  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 <u>circle</u> or <u>underline</u> the specific tics that the patient has experienced (circle or underline the words that apply).

[In Years]

Ever	Cur- rent	Age of	The patient has experienced, or others have noticed, involuntary and apparently purposeless bouts of:	Ver
		onset	, .	
			-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.	
	1		-head jerks/movements.	1
			touching the shoulder with the chin or lifting the chin up.	
			throwing the head back, as if to get hair out of the eyes.	
	1		-shoulder jerks/movements.	
			jerking a shoulder.	
			shrugging the shoulder as if to say "I don't know."	
	1	П	-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.	
		I	-leg, foot or toe movements.	1
			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.	

-abdominal/trunk/pelvis movements.  tensing the abdomen, tensing the buttocksother simple motor tics.  Please write example(s):
tensing the abdomen, tensing the buttocksother simple motor tics.
tensing the abdomen, tensing the buttocksother simple motor tics.
-other simple motor tics.
-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:
tia like behaviors that sould injure/mutilate others. Please describe.
tic-like behaviors that could injure/mutilate others. Please describe:
self-injurious tic-like behavior(s). Please describe:
Sch-injurious tie-fike behavior(s). Trease describe.
-other involuntary and apparently purposeless motor tics (that do not f
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 <b>first</b> vocal tics?	years old.
Describe <b>first</b> 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  $(\mathbf{x})$  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 <u>circle</u> or <u>underline</u> the specific tics that the patient has experienced (circle or underline the words that apply).

[In Years]

Ever	Cur-	Age	The patient has experienced, or others have noticed, bouts of	Ver
	rent	of	involuntary and apparently purposeless utterance of:	
		onset		
			-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 as 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
<b>RARELY</b> 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
<b>OCCASIONALLY</b> 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
<b>FREQUENTLY</b> 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
<b>ALMOST ALWAYS</b> 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
<b>ALWAYS</b> 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
<b>MODERATE INTENSITY</b> 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
<b>SEVERE INTENSITY</b> 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
<b>MARKED</b> 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
<b>SEVERE</b> 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
<b>MODERATE</b> When tics are present, they frequently interrupt the flow of behavior or speech.	0	0	3
<b>MARKED</b> When tics are present, they frequently interrupt the flow of behavior or speech, and they occasionally disrupt intended action or communication.	0	0	4
<b>SEVERE</b> When tics are present, they frequently disrupt intended action or communication.	0	0	5

## **IMPAIRMENT**

NONE	0	0
<b>MINIMAL</b> 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
<b>MODERATE</b> 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
<b>MARKED</b> Tics associated with major difficulties in self-esteem, family life, social acceptance, or school or job functioning.	0	40
<b>SEVERE</b> 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)	