



Estimating the number of people with Tourette syndrome and persistent tic disorder in the United States

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ABSTRACT

Estimates of the number of people in the U.S. with Tourette syndrome or other persistent tic disorders can inform service provision planning. Based on available prevalence estimates applied to 2020 population data from the U.S. Census, we estimated that 350,000–450,000 U.S. children and adults have Tourette syndrome and about one million have other persistent tic disorders. Variation across studies makes estimating the total number of people in the United States affected by these disorders challenging. More precise measurement could ensure that prevalence estimates accurately reflect all who are impacted by these disorders and who could benefit from evidence-based services.

Tourette syndrome is a neurodevelopmental disorder involving the presence of at least two motor tics and at least one vocal tic for a year or more, based on the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) (American Psychiatric Association, 2013). The DSM-5 defines persistent tic disorder (previously called chronic tic disorder (American Psychiatric Association, 1994)) as the presence of at least one motor tic or at least one vocal tic for at least a year (American Psychiatric Association, 2013). Symptoms of tic disorders (i.e., tics) tend to appear when children are 4–7 years of age, peak at ages 9–12 years, and subside during adolescence, and are more commonly reported in boys than girls (Bloch and Leckman, 2009; Murphy et al., 2013). People with Tourette syndrome or other persistent tic disorders can experience co-occurring disorders, functional impairments, discrimination, and bullying victimization or perpetration (Charania et al., 2022; Conelea et al., 2011, 2013). Many people with Tourette syndrome and other persistent tic disorders can benefit from psychoeducation about tic disorders, behavioral treatments, and/or medication (Murphy et al., 2013; Pringsheim et al., 2019). Estimating the prevalence of Tourette syndrome and other persistent tic disorders is challenging due to limited availability of population-based data. Available data often rely on report of a previous diagnosis and will miss individuals who have not been diagnosed. Prevalence estimates of these disorders, and the corresponding number of people with the disorder, can inform service provision planning by health systems, payors, and state and local decision-makers. The objective of this analysis is to estimate the number of people in the

United States with Tourette syndrome or persistent tic disorder based on the range of available prevalence estimates.

Data from the 2016 to 2017 National Survey of Children's Health (NSCH) show that of children ages 6–17 years in the United States, 0.30% had ever been diagnosed with Tourette syndrome based on parent report, and 0.27% currently had Tourette syndrome (Charania et al., 2022). The prevalence of ever having been diagnosed with Tourette syndrome has been consistent in NSCH data over time, with estimates of 0.30% and 0.28% from the 2007 and 2011–2012 data, respectively (Bitsko et al., 2014; Scahill et al., 2009). NSCH and other U.S. national surveys do not include indicators of diagnosed persistent tic disorders, nor do U.S. national surveys include indicators of diagnosed tic disorders in adults.

Results from two partially overlapping meta-analyses showed similar population-level Tourette syndrome prevalence estimates among children of 0.77% (95% confidence interval [CI]: 0.39%, 1.51%), based on 13 studies (Knight et al., 2012), and 0.52% (95% CI: 0.32%, 0.85%), based on 21 studies (Scharf et al., 2015). Studies included in those meta-analyses, which were not limited to U.S. populations, used population-based screening or diagnostic assessments to identify Tourette syndrome, and therefore included children who had not previously been diagnosed. Comparing these estimates to those from NSCH suggests that more than half of children who meet criteria for Tourette syndrome may not have received a diagnosis.

Fewer studies have estimated the prevalence of current Tourette syndrome specifically in older adolescents or adults. The pooled

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population-based prevalence of Tourette syndrome from two studies of 16- and 17-year-old military recruits in Israel was 0.05% (95% CI: 0.03%, 0.08%) (Knight et al., 2012). This estimate is similar to the estimate based on a nationally representative survey in Canada (0.07%, 95% CI: 0.04, 0.09) for adults aged 18 years and older with diagnosed Tourette syndrome (Yang et al., 2016).

Population-based data on the prevalence of current persistent tic disorders other than Tourette syndrome in children or adults are also limited. A meta-analysis of three studies showed a pooled prevalence of 1.61% (95% CI: 0.92%, 2.83%) for persistent tic disorder in children (Knight et al., 2012). One of the studies in that meta-analysis included Tourette syndrome in the persistent tic disorder category and had a prevalence estimate of 1.27% (Snider et al., 2002). The other two studies included estimates for Tourette syndrome and persistent tic disorders separately. Adding the mutually exclusive Tourette syndrome and persistent tic disorder categories together from those other two studies, each of which had a larger sample size, yields prevalence estimates of 1.40% (Nomoto and Machiyama, 1990) and 3.04% (Stefanoff et al., 2008) for a combined estimate of any persistent tic disorder.

The variation in prevalence estimates of Tourette syndrome and persistent tic disorders across studies makes estimating the total number of people in the United States affected by these disorders challenging. We calculated a range of estimates using the available prevalence estimates and the 2020 Census population estimates (U.S. Census Bureau, 2020) (Table 1), similar to the methods used by Stern and colleagues to estimate the number of people in the United Kingdom with Tourette syndrome (Stern et al., 2005). Using the Scharf et al and Knight et al pooled prevalence estimates, approximately 350,000 to 450,000 U.S. children and adults are estimated to be living with Tourette syndrome. This value ranges from approximately 57,000 to 3.6 million people based on prevalence estimates from individual studies included in the meta-analyses (Costello et al., 1996; Cubo et al., 2011). Similarly, the estimated number of people in the United States with persistent tic disorders other than Tourette syndrome is approximately one million based on the pooled estimates from the Knight et al. meta-analysis, but varies from approximately 560,000 to almost 1.7 million using prevalence estimates from individual studies (Nomoto and Machiyama, 1990; Stefanoff et al., 2008). Adding the pooled estimates together suggests that about 1.4 million people in the United States may be affected by Tourette syndrome or other persistent tic disorders.

Although these rough approximations are useful for informing national-level and visibility-raising efforts, more precise measurement could ensure that the prevalence estimates of Tourette syndrome and other persistent tic disorders accurately reflect all who are impacted by these disorders and who could benefit from evidence-based services. In addition, prevalence estimates within smaller geographic units (e.g., states, communities) would support data-informed planning by health systems, payors, and other decision-makers to promote the best outcomes for people affected by Tourette syndrome and other persistent tic disorders.

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Table 1

Estimates of the number of people with Tourette syndrome (TS) and other persistent tic disorders (PTD) in the United States based on various prevalence estimates applied to 2020 U.S. Census data.

Description	Prevalence estimate		Estimated number in the United States
	5-14 years	15+ years	
TOURETTE SYNDROME (TS)			
Scharf et al. (2015) TS estimate in children; Knight et al. (2012) estimate for adults ¹	0.52%	0.05%	347,653
Knight et al. (2012) TS estimate in children; Knight et al. (2012) estimate for adults ¹	0.77%	0.05%	420,438
Lowest TS prevalence estimate from all studies included in meta-analyses – Costello et al. (1996) ²	0.04%	0.0024% (6% of child estimate) ³	57,177
Highest TS prevalence estimate from all studies included in meta-analyses – Cubo et al. (2011)	5.26%	0.53% (10% of child estimate) ³	3,570,803
PERSISTENT TIC DISORDER (PTD)			
Knight et al. (2012) pooled PTD estimate	1.61% ⁴	0.10% (6% of child estimate) ³	929,655
Knight et al. (2012) pooled PTD estimate	1.61% ⁴	0.161% (10% of child estimate) ³	1,092,964
Lowest PTD estimate – Nomoto and Machiyama (1990)	0.985%	0.0591% (6% of child estimate) ³	563,309
Highest PTD estimate – Stefanoff et al. (2008)	2.47%	0.247% (10% of child estimate) ³	1,676,716
TS AND PTD COMBINED			
Knight et al. (2012) pooled estimates for TS and PTD	0.77% + 1.61% = 2.38%	0.143% (6% of child estimate) ³	1,360,816
Scharf et al. (2015) pooled estimate for TS and Knight et al. (2012) pooled estimate for PTD	0.52% + 1.61% = 2.13%	0.213% (10% of child estimate) ³	1,445,972

¹ Only the Knight et al., 2012 meta-analysis provided a summary estimate for TS prevalence in adults

² The lowest TS prevalence estimate in the Scharf et al., 2015 meta-analysis (Apter, 1993) was one of the two studies of people 16-17 years of age that forms the basis of the estimate for all those 15+ years of age, and so was not used as an estimate of prevalence in children ages 5-14 years of age in our calculations.

³ The only pooled meta-analysis prevalence estimate available for adults is from Knight et al. 2012 (0.05%). That value is ~10% of the childhood pooled prevalence estimate from the Scharf et al., 2015 meta-analysis (0.05%/0.52%) and ~6% of the childhood pooled prevalence estimate from the Knight et al. 2012 meta-analysis (0.05%/0.77%).

⁴ One of the three studies included in the pooled estimate for PTD combined TS and PTD (Snider et al., 2002).

CRedit authorship contribution statement

Sarah C. Tinker: Conceptualization, Investigation, Methodology, Writing – original draft. **Rebecca H. Bitsko:** Conceptualization, Investigation, Writing – review & editing. **Melissa L. Danielson:** Investigation, Writing – review & editing. **Kimberly Newsome:** Investigation, Writing – review & editing. **Jennifer W. Kaminski:** Writing – review & editing, Supervision.

Declarations of Competing Interest

The authors report no conflicts of interest.

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