



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[60Day-24-24EG; Docket No. CDC-2024-0024]

Proposed Data Collection Submitted for Public Comment and Recommendations

AGENCY: Centers for Disease Control and Prevention (CDC), Department of Health and Human Services (HHS).

ACTION: Notice with comment period.

SUMMARY: The Centers for Disease Control and Prevention (CDC), as part of its continuing effort to reduce public burden and maximize the utility of government information, invites the general public and other federal agencies the opportunity to comment on a proposed information collection, as required by the Paperwork Reduction Act of 1995. This notice invites comment on a proposed information collection project titled Documenting outcomes associated with Persistent Tic Disorders (including Tourette Syndrome) in Children, Adolescents, and Young Adults through Surveillance. This study will collect data on the public health impact of persistent tic disorders from children and adolescents with tic disorders and their parents, as well as young adults with tic disorders.

DATES: CDC must receive written comments on or before [INSERT DATE 60 DAYS AFTER PUBLICATION DATE IN THE FEDERAL REGISTER].

ADDRESSES: You may submit comments, identified by Docket No. CDC-2024-0024 by either of the following methods:

- Federal eRulemaking Portal: www.regulations.gov. Follow the instructions for submitting comments.
- Mail: Jeffrey M. Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, NE, MS H21-8, Atlanta, Georgia 30329.

Instructions: All submissions received must include the agency name and Docket Number.

CDC will post, without change, all relevant comments to www.regulations.gov.

Please note: Submit all comments through the Federal eRulemaking portal

(www.regulations.gov) or by U.S. mail to the address listed above.

FOR FURTHER INFORMATION CONTACT: To request more information on the proposed project or to obtain a copy of the information collection plan and instruments, contact Jeffrey M. Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, NE, MS H21-8, Atlanta, Georgia 30329; Telephone: 404-639-7570; E-mail: omb@cdc.gov.

SUPPLEMENTARY INFORMATION:

Under the Paperwork Reduction Act of 1995 (PRA) (44 U.S.C. 3501-3520), federal agencies must obtain approval from the Office of Management and Budget (OMB) for each collection of information they conduct or sponsor. In addition, the PRA also requires federal agencies to provide a 60-day notice in the *Federal Register* concerning each proposed collection of information, including each new proposed collection, each proposed extension of existing collection of information, and each reinstatement of previously approved information collection before submitting the collection to the OMB for approval. To comply with this requirement, we are publishing this notice of a proposed data collection as described below.

The OMB is particularly interested in comments that will help:

1. Evaluate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility;
2. Evaluate the accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used;
3. Enhance the quality, utility, and clarity of the information to be collected;

4. Minimize the burden of the collection of information on those who are to respond, including through the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of information technology, e.g., permitting electronic submissions of responses; and
5. Assess information collection costs.

Proposed Project

Documenting outcomes associated with Persistent Tic Disorders (including Tourette Syndrome) in Children, Adolescents, and Young Adults through Surveillance – New – National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC).

Background and Brief Description

There are an estimated 1.4 million people in the U.S. affected by persistent tic disorders (PTD), including Tourette syndrome (TS). To support people with these conditions, the impact of PTD/TS must be understood. Although some data on the impact of PTD/TS on social relationships and education are available, other potential outcomes associated with PTD/TS have not been well-documented; including associated costs, suicidality, health care transition, and the prevalence of co-occurring disorders and how co-occurring disorders modify these outcomes. Limited data are available on how these outcomes may differ among sub-populations (e.g., by sex, race/ethnicity, age group, and geography [e.g., urban/rural]).

This data collection aims to document priority outcomes including costs (e.g., education level, employment, healthcare beyond those available in claims data), prevalence of suicidality risk, transition to adult healthcare, and the prevalence of co-occurring conditions and how they modify these outcomes among children and adolescents (4-17 years) and young adults (18-26 years) with PTD/TS. Data will be collected once from a participant (i.e., individuals with

PTD/TS and/or their caregiver), via a survey, and a clinical assessment of tic symptoms. All questions for the Tic Impact Surveillance Survey, the survey created for this surveillance project, were selected from national surveys or previously validated measures. This will allow us to compare estimates from the Tic Impact Surveillance Survey to external prevalence estimates for the same health indicators in US children, adolescents, and young adults in the general population and to previously published findings. Data will be used to inform where resources for families and healthcare providers (e.g., professional trainings) are most needed to support people with PTD/TS and their families and to address health inequities among the population.

CDC requests OMB approval for an estimated 401 annual burden hours. There is no cost to respondents other than their time to participate.

Estimated Annualized Burden Hours

Type of Respondents	Form Name	Number of Respondents	Number of Responses per Respondent	Average Burden per Response (in hours)	Total Burden (in hours)
Parents of children 4-17 years with a persistent tic disorder	Parent	225	1	45/60	169
Children 4-8 years with a persistent tic disorder	Child 4-8	30	1	20/60	10
Children 9-11 years with a persistent tic disorder	Child 9-11	45	1	45/60	34
Adolescents (teens) 12-17 years with a persistent tic disorder	Adolescent	150	1	45/60	113
Adults (18-26 years) with a persistent tic disorder	Adult	75	1	1	75
Total					401

Jeffrey M. Zirger,

Lead,

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Office of Public Health Ethics and Regulations,

Office of Science,

Centers for Disease Control and Prevention.

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