e: 4163-18-P

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[30Day-25-24EG]

Agency Forms Undergoing Paperwork Reduction Act Review

In accordance with the Paperwork Reduction Act of 1995, the Centers for Disease Control and Prevention (CDC) has submitted the information collection request titled “Documenting Outcomes Associated with Persistent Tic Disorders (including Tourette Syndrome) in Children, Adolescents, and Young Adults through Surveillance” to the Office of Management and Budget (OMB) for review and approval. CDC previously published a “Proposed Data Collection Submitted for Public Comment and Recommendations” notice on April 5, 2024 to obtain comments from the public and affected agencies. CDC did not receive comments related to the previous notice. This notice serves to allow an additional 30 days for public and affected agency comments.

CDC will accept all comments for this proposed information collection project. The Office of Management and Budget is particularly interested in comments that:

(a) 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;

(b) Evaluate the accuracy of the agencies estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used;

(c) Enhance the quality, utility, and clarity of the information to be collected;

(d) 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 submission of responses; and

(e) Assess information collection costs.

To request additional information on the proposed project or to obtain a copy of the information collection plan and instruments, call (404) 639-7570. Comments and recommendations for the proposed information collection should be sent within 30 days of publication of this notice to www.reginfo.gov/public/do/PRAMain. Find this particular information collection by selecting "Currently under 30-day Review - Open for Public Comments" or by using the search function. Direct written comments and/or suggestions regarding the items contained in this notice to the Attention: CDC Desk Officer, Office of Management and Budget, 725 17th Street, NW, Washington, DC 20503 or by fax to (202) 395-5806. Provide written comments within 30 days of notice publication.

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) or 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. We will also extract data from medical records. Most questions for the survey created for this surveillance project were selected from national surveys or previously validated measures. This will allow us to compare estimates from this project to external prevalence estimates for the same health indicators in U.S. 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 differences in health among subgroups of the population.

As a result of working with awardees to finalize measures, and decisions to rely on parent-report for the majority of indicators for this age group, CDC has updated the burden estimates for this data collection. CDC requests OMB approval for an estimated 500 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)
Parents of children 4–17 years with a persistent tic disorder	Parent	300	1	45/60
Children 4–8 years with a persistent tic disorder	Child 4–8	60	1	20/60
Children 9–11 years with a persistent tic disorder	Child 9–11	100	1	30/60

Adolescents (teens) 12–17 years with a persistent tic disorder	Adolescent	140	1	45/60
Adults (18–26 years) with a persistent tic disorder	Adult	100	1	1

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