: 4163-18-P

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[60Day-26-0179; Docket No. CDC-2026-0694]

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 Focus on Advancing Support and Transition with the Fragile X Online Registry With Accessible Database (FAST FORWARD). This surveillance project will allow CDC to better understand health outcomes, educational and social outcomes and gaps in related services (education, work, well-being, etc.), and barriers to and differences in receipt of healthcare and other services among people with fragile X syndrome (FXS).

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

ADDRESSES: You may submit comments, identified by Docket No. CDC-2026-0694 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, N.E., 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, N.E., MS H21-8, Atlanta, Georgia 30329; phone: 404-639-7118; 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

Focus on Advancing Support and Transition with the Fragile X Online Registry with Accessible Research Database (FAST FORWARD) – New - National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC).

Background and Brief Description

Fragile X Syndrome (FXS) is a genetic disorder caused by changes in a gene called fragile x messenger ribonucleoprotein 1 (FMR1). FMR1 usually makes a protein called Fragile X Messenger Ribonucleoprotein (FMRP) that is needed for brain development. People with FXS make little or no FMRP. FXS is the most prevalent known cause of inherited intellectual disability and the most common monogenic cause of autism. Physical features of FXS include a narrow face with prominent jaw and forehead and large ears. Medical features can include dental crowning, otitis media, sinus infections, sleep disorder, and strabismus; developmental features can include intellectual disability, motor delays, poor eye contact, repetitive behaviors, seizure disorder, speech-language disorder, and symptoms of attention deficit hyperactivity disorder. FXS is typically diagnosed in early childhood when physical, medical, and developmental features are more recognized. It is estimated that one in 7,000 males and one in 11,000 females have FXS.

The proposed data collection builds on and improves upon four previous CDC-funded data collection efforts focused on FXS. The first project (CDC-RFA-DD-07-003; 2008-2011) piloted an infrastructure to conduct data collection on people with FXS across multiple sites. The second project (CDC-RFA-DD-11-007; 2011-2015) developed and piloted the infrastructure for

a registry and for longitudinal data collection. The third project (CDC-RFA-DD-15-003; 2015-2020), which established the Fragile X Online Registry With Accessible Research Database (FORWARD), and the fourth project (CDC-RFA-DD-21-002; 2021-2026), which extended FORWARD to include Multiple Assessments for Research Characterization (FORWARD-MARCH) built on the foundation of the first two projects and continued data collection to conduct analyses to better characterize the natural history of FXS and meaningful outcome measures to improve the lives of people with FXS.

Congressional language accompanying the 2026 Consolidated Appropriations Act funding for CDC's FXS activities encourages CDC to support additional strategies to promote earlier identification of children with FXS, to ensure populations with FXS conditions are being properly diagnosed and are made aware of available medical services, and support people with FXS and associated conditions and disorders across the lifespan.

The current information collection request, consistent with Congressional intent, is to employ clinic-based enrollment of eligible participants aged 40 years old or younger with full mutation of FXS that attend the three U.S. clinics funded for this project. Each participating clinic will recruit a minimum of 200 eligible persons with FXS (approximately 40 per year for a total of 600 across all three sites. Information will be collected on diagnosis, co-occurring conditions and behaviors, communication, adaptive abilities, healthcare utilization and service needs, education, transition planning and experience, activities and social participation, future planning, caregiver supports, demographics, participant strengths, and other topics consistent with the goals of the project. Data will be collected through online caregiver surveys.

CDC requests OMB approval for an estimated 600 annual burden hours. There are no costs 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	Total Burden (in hours)

				hours)	
Parents/ Caregivers	Survey	600	1	1	600
Total					600

Jeffrey M. Zirger,

Lead,

Information Collection Review Office,

Office of Public Health Ethics and Regulations,

Office of Science,

Centers for Disease Control and Prevention.

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