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) 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.

This information collection request (ICR), consistent with Congressional intent, is developed to employ clinic-based enrollment of eligible participants aged 40 years old or younger with full mutation of FXS that attend clinics affiliated with the three U.S. sites funded for this project. Each participating clinic will recruit a minimum of 200 eligible persons with FXS 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 200 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 hours)
Parents/Caregivers	Survey	200	1	1

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[FR Doc. 2026–22329 Filed 10–30–26; 8:45 am]

BILLING CODE 4163–18–P

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[30Day–27–1291]

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 ''Generic Information Collection Request for Cognitive Testing and Pilot Testing for the National Center for Chronic Disease Prevention and Health Promotion'' 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 March 9, 2026, to obtain comments from the public and affected agencies. CDC received one comment 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

Generic Information Collection Request for Cognitive Testing and Pilot Testing for the National Center for Chronic Disease Prevention and Health Promotion (OMB Control No. 0920–1291, Exp. 5/31/2026)—Reinstatement—National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Centers for Disease Control and Prevention (CDC).

Background and Brief Description

CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) established a Generic Clearance to support information collection for cognitive testing and pilot testing activities.

Information collections that support the Behavioral Risk Factor Surveillance System (BRFSS) and other NCCDPHP programs are expected to be the major focus of activity under this Generic Clearance. Additional information collections may also be considered for submission through this Generic Clearance if they are relevant to BRFSS and NCCDPHP programs or collaborations.

Cognitive testing and pilot testing are methodological procedures conducted to prepare for a large scale or key information collection. Cognitive and pilot testing activities are designed to improve information quality and the efficiency of information collection by addressing issues such as the use of new or existing survey questions, question formatting, survey protocols, data collection software systems and other related processes.

Cognitive testing is a technique used to clarify the meaning of survey questions and/or the response options for questions. Cognitive testing contributes to the understanding of the validity and reliability of questions used for a variety of public health purposes. Cognitive testing is conducted early in the process of considering questions for use in a survey or other information collection activity. This type of testing is usually conducted in a controlled setting, such as an office. Respondents participate in a discussion or interview with a trained interviewer and may respond individually or as members of focus groups.

Questions may undergo cognitive testing because they have not been used in previous surveys; for example, questions related to the emergence of a new public health concern (such as e-cigarettes). In addition, testing may be conducted on previously used questions to assess their use in a different information collection mode; for example, testing might be conducted to convert questions developed for a paper survey to an interview format or an electronic survey format; or testing might be conducted to identify issues specific to a subpopulation or language translation. Respondents are asked to review questions and/or surveys to discuss their impressions of the items under consideration, the questions, the response set, individual words within the question, or the focus of the questionnaire itself. Incentives may be offered to respondents who participate in the in-person phase of cognitive testing since these activities involve additional burden and inconvenience.

Pilot testing is used to determine whether methods or modes of data collection (such as phone or mail surveys, in-person interviews or online data collection) are appropriate and efficient ways of collecting data. Pilot testing may include testing of changes in sampling or contacting potential respondents.

The majority of participants in cognitive and pilot testing activities are expected to be adults >18 years of age. Information may be collected during the recruitment process to assist in the selection of respondents. Respondents may be recruited to take part in testing through online or newspaper advertisements. If the participants are not recruited to be present at a physical location, they may be called and recruited by telephone.

Cognitive and pilot testing are efficient means of identifying problems with questions and procedures prior to implementation of data collection. Thus, they are cost effective approaches to providing evidence on survey questionnaire performance. A consequence of cognitive and pilot testing is to maintain high levels of participation in the information collection process itself.

Initial response and burden estimates are based on anticipated information collection needs for the Generic Information Collection Request for Cognitive Testing and Pilot Testing for the National Center for Chronic Disease Prevention and Health Promotion, with an additional allocation for a variety of NCCDPHP programs and collaborators. Each information collection activity conducted through this Generic Clearance will be submitted to OMB for approval in a project-specific information collection request package that describes its purpose and methods.

Participation in cognitive and pilot testing is voluntary, but respondents will be encouraged to participate by explanations of the need for their input in the introduction of each survey. CDC requests OMB approval for an estimated 11,450 annual burden hours. There are no costs to respondents other than their time.

ESTIMATED ANNUALIZED BURDEN HOURS

Type of respondent	Form name	Number of respondents	Number of responses per respondent	Average burden per response (in hours)
General U.S. Population or Selected Sub-population.	Screening for cognitive testing	2,500	1	15/60
	Screening for pilot testing	2,400	1	15/60
	Cognitive testing in person	1,500	1	60/60
	Cognitive testing by phone	1,500	1	45/60
	Cognitive testing by ABS/mail/web	600	1	60/60
	Pilot testing in person	1,000	1	30/60
	Pilot testing by phone	3,000	1	30/60
	Pilot testing by ABS/mail/web	10,000	1	30/60

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[FR Doc. 2026–22330 Filed 10–30–26; 8:45 am]

BILLING CODE 4163–18–P