

Supporting Statement for the Chronic Disease Self-Management Education Program Standardized Data Collection

A. Justification

1. Circumstances Making the Collection of Data Necessary

Background

This is a revision of a currently approved collection.

The Administration on Aging (AoA), part of the Administration for Community Living (ACL), will use the proposed set of data collection tools to monitor grantees receiving “Empowering Older Adults and Adults with Disabilities through Chronic Disease Self-Management Education (CDSME)” cooperative agreements. Most recently, through funding provided by 2019 Prevention and Public Health Funds, ACL awarded 11 cooperative agreements for a three-year project period beginning May 1, 2019.

Grantee agencies represent a variety of organization types, including state agencies (aging and public health), area agencies on aging, universities, and nonprofit organizations. Grantees are tasked with two primary goals: (1) significantly increase the number of older adults and adults with disabilities who participate in CDSME and self-management support programs and (2) develop a sustainable infrastructure for these proven interventions.

The most widely disseminated CDSME is the [Chronic Disease Self-Management Program \(CDSMP\)](#), originally developed at Stanford University. In addition to the English version of the CDSMP, which is appropriate for any type of chronic condition, other evidence-based self-management education programs have been developed for individuals with diabetes, chronic pain, or HIV, those with cancer or cancer survivors, for Spanish-speaking individuals, and in an internet format.

Additionally, self-management support programs spanning topics such as behavioral health, physical activity, and medication management are supported through this funding initiative.

Grantees collect information at both the workshop and participant level. Specific to the workshop, information on workshop type, location, start/end date, etc. is collected. At the participant level, de-identified demographic and health status information is collected.

AoA funds the National Council on Aging (NCOA) to serve as the National CDSME Resource Center and provide technical assistance (TA) to grantees as well as the broader network of organizations implementing CDSME and self-management support programs.

NCOA created an online database that grantees and other program sites use to provide data on their workshops. This system allows AoA to regularly monitor grantee performance status, including data analysis, maps, comparative charts, and identification of high- and low-performing grantees in order to identify and target technical assistance needs.

AoA will use this set of data collection tools to monitor 29 grantees that were awarded cooperative agreements in response to the “Empowering Older Adults and Adults with Disabilities through Chronic Disease Self-Management Education Programs” funding opportunities competed in 2017, 2018, and 2019. These data collection tools will also be used for future CDSME cooperative agreements.

AoA will use the information to: 1) comply with reporting requirements mandated by the authorizing statutes; 2) collect data for performance measures used in the justification of the budget to Congress and by program, state, and national decision makers; 3) effectively manage the CDSME program at the federal, state, and local levels; 4) identify program implementation issues and technical assistance needs; 5) identify best practices to serve as the basis for developing resources to help grantees learn from and replicate these practices; and 6) provide information for reports to Congress, other government agencies, stakeholders, and to the public about grantee progress. Data will be collected from grantee staff and program staff/volunteers involved in delivering CDSME workshops, as well as individuals who participate in CDSME workshops.

Legal and Administrative Requirements

The statutory authority for applicable grant awards is contained in the Department of Defense and Labor, Health and Human Services, and Education Appropriations Act, 2019 and Continuing Appropriations Act, 2019, Pub.L.115-245; Public Health Service Act, 42 U.S.C. §§ 300u-2 (Community Programs) and 300u-3 (Information Programs); and the Patient Protection and Affordable Care Act, 42 U.S.C. § 300u-11 (Prevention and Public Health Fund).

2. Purpose and Use of the Information Collection

AoA will use the information from the CDSME data collection tools to:

- 1) Comply with reporting requirements required by the authorizing statutes;
- 2) Collect data for performance measures used in the justification of the budget to Congress and by program, state and national decision makers;
- 3) Effectively manage the CDSME program at the federal, state, and local levels,
- 4) Identify program implementation issues and pinpoint areas for technical assistance activities;

- 5) Identify best practices in program implementation and building sustainable program delivery systems and to develop resources to enable current and future grantees to learn from and replicate these practices; and
- 6) Provide information for reports to Congress, other governmental agencies, stakeholders, and to the public about CDSME grantee progress.

Information from the CDSME data collection tools will also be provided to federal and state legislators; state agencies on aging and state health departments; national, state and local organizations with an interest in evidence-based self-management education programs and healthy aging issues; current and future CDSME grantees; and private citizens who request it. Compiled information will be posted on ACL's website, as well as NCOA's technical assistance website.

AoA proposes to adapt the previously approved tools that have successfully been used to monitor the progress of ACL's prior cohorts CDSME grantees. The following types of tools included in the collection and purposes of each are:

- Program data collection tools are paper tools used to collect information at each workshop/ program series:
 - A **Program Information Cover Sheet** and an **Attendance Log** are completed by the workshop leaders/delivery personnel. This information documents the location of the workshop, type of program, and the number of participants who completed at least four out of the six workshop sessions (for those interventions with a finite end date), the recommended intervention dose.
 - A **Participant Information Survey**, documenting participants' demographic and health characteristics. At the end of each program, local data entry staff or volunteers will enter information from the Program Information Cover Sheet and Participant Information Surveys into the national CDSME database.

Examples of products developed resulting from these data collection efforts are available at: <https://www.ncoa.org/center-for-healthy-aging/cdsme-resource-center/>.

3. Use of Improved Information Technology and Burden Reduction

The proposed CDSME data collection tools will utilize the same procedures and online data entry system utilized since 2010. The existing national database is maintained by NCOA through an AoA cooperative agreement. Feedback about this system has been very positive. It is considered very user-friendly. States are not charged any licensing or usage fees to access the system. NCOA provides training and technical assistance regarding the use of the system when requested.

4. Efforts to Identify Duplication and Use of Similar Information

There is no similar data collection; all information in the proposed data tools are unique to the CDSME program grantees.

5. Impact on Small Businesses or Other Small Entities

No small businesses will be involved in this effort.

6. Consequences of Collecting the Information Less Frequently

CDSME grantees will submit data on an ongoing basis (upon program completion). To meet the statutory requirements and execute program management functions, availability of timely data is critical. The project period for current grantees is 36 months. If data was only submitted semi-annually or annually, AoA would be unable to promptly identify grantees in need of technical assistance to reach their goals (numbers served, numbers of underserved populations reached, extent to which they are building sustainable systems etc.).

7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

This request is consistent with the general information collection guidelines of 5 CFR 1320.5(d)(2). No special circumstances apply.

8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency

As required by 5 CFR 1320.8(d), a 60-day notice was published in the Federal Register on July 9, 2019, Volume 84, page 32746. Thirteen public comments were received.

AoA encouraged current and former grantees to respond to the Federal Register notice through multiple reminders sent out to grantee points of contact.

In addition to internal feedback solicited from colleagues within ACL’s Center for Policy and Evaluation, input was also gathered from a focus group of current CDSME grantees.

ACL published a 30-day Federal Register Notice on October 23, 2019, Volume 84, pages 56813-5681.

60-Day Comments and Responses

ACL received comments from thirteen organizations/individuals in response to the 60-FRN for the proposed revisions to the information collection requirements related to ACL’s Chronic Disease Self-Management Education grant program. ACL reviewed all of the comments, though one was deemed irrelevant to the information collection requirements. The ACL responses for each topic/issue are detailed below:

Participant Information Survey

Topic/Issue	Comment	ACL Response
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Participant ID	More than one respondent indicated that the unique identifier is cumbersome and presents an opportunity for mistakes due to its length. Also a comment that the change may make it difficult to evaluate at the individual level across years.	Compared to previous versions, the Participant ID is now to be completed by onsite staff and/or program leaders. The National CDSME Resource Center will be providing training and technical assistance on the best strategies for documenting the Participant ID. The change is primarily driven by increased attention to the application of the highest standards for safeguarding data collected by our grantees. After extensive review of evidence-based program data collection processes, ACL and the Resource Center are working to elevate standards to ensure the privacy and security of all data collected from participants. As such, the use of the existing Participant ID, which includes components of the participants' names and year of birth, could potentially provide clues into the person's identity, especially if coupled with other demographic data.
Provider Referral	Specific to Question #1 (Did your health care provider suggest that you take this program?), replace the word "take" with "attend."	ACL will incorporate this suggested revision.
Sex/Gender	More than one respondent suggested the incorporation of a non-binary response option, in addition to male/female. Suggestion to delineate either sex or gender (question currently reads, "Are you...male/female?").	As a federal agency, ACL references the American Community Survey (implemented by the Census Bureau) as a benchmark for demographic questions. To remain consistent with the U.S. Census/American Community Survey, ACL will continue to use male/female response options. This wording has been used for the past 6 years without issue and preserves data collection continuity.
LGBTQ Identification	Suggestion to incorporate a question to allow individuals to self-identify their sexual orientation.	As noted previously, ACL works to align our data collection with what is collected by the U.S. Census around demographic information. Census does not currently collect information on sexual orientation.
Chronic Conditions List	Suggestion to add HIV to chronic conditions list.	Collection of HIV/AIDS data requires additional special care in the collection and sharing of this data because persons with HIV/AIDS can face discrimination. In some

		<p>states, added protections require providers to request additional permission from the patient to share information related to HIV/AIDS status.</p> <p>HIV/AIDS has not been asked in prior iterations of this survey. Centers for Medicare & Medicaid Services (CMS) data from 2017 shows that across all beneficiaries (age 65+), HIV/AIDS accounted for .1% of cases nationally. The goal is not to capture an exhaustive list of chronic conditions; rather, the most common based the public data and the experience of current/prior grantees. This question also allows participants to select ‘Other’ (without an open-ended response).</p>
<p>Social Isolation</p>	<p>Multiple comments received, as detailed below:</p> <p>Truncate Question #16 (How often do you feel lonely or isolated from those around you?) to remove “from those around you” at end.</p> <p>Question #16 (and corresponding post-test Question #3) adds to the survey length and may be perceived by some as intrusive. Additionally, wording may be off-putting for participants who are expecting a positive, strengths-based experience.</p> <p>Specific to post-test Question #3, comment that item is not likely to show change from pre- to post-, especially given the negative direction. Suggestion to ask at post-test only and frame as</p>	<p>The item stems from validated tools in the National Institutes of Health’s PROMIS item bank (v2.0) – Social Isolation. The original version is written in the first person. Loneliness was added to improve literacy (reduce grade level).</p> <p>It is also an adaptation from the UCLA Loneliness Scale (v3, #14). “How often do you feel isolated from others?” (Never to Always), which has been extensively used for decades (Russell, 1996). It continues to be validated with older adults (Ausin et al, 2019; Domenech-Abella, et al, 2017).</p> <p>The item has also been used successfully by CMS in social screening efforts (Accountable Health Communities Health-Related Social Needs Screening), as well as Kaiser Permanente.</p> <p>ACL appreciates the suggestion to collect more data but has decided in the interest of balancing data collection and burden to not include additional elements on the survey.</p>

	<p>“After taking this class, how much more connected to others do you feel?” or something similar.</p> <p>Comment that a single social isolation question may not provide useful information. Suggestion to include sub-questions specific to companionship, worry about being alone, shared interests and ideas, and participation in social clubs or religious groups.</p>	
Chronic Conditions Language	Suggestion to replace “chronic” health condition(s) with “ongoing” health condition(s).	ACL appreciates that “ongoing” may be considered synonymous with “chronic”; however, we will continue to use the term chronic, as this is the vernacular generally used within the US Department of Health and Human Services (e.g. Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, etc.).
For Whom Attending Program	Comment that Question #12 (For whom are you attending this program?) lengthens the questionnaire without substantial benefit (purpose is unclear).	ACL agrees with this comment; we will remove the question from the survey.
Disability Status	<p>Proposed revision to Question #15 includes three sub-parts to independently assess various facets of disability status; the current version combines all three parts into a single item. Suggestion to keep question as is (single item).</p> <p>A comment was received</p>	<p>The six-item set of questions used in the American Community Survey (ACS) are the minimum standard for disability survey questions. Questions and answers in this set cannot be changed. The six questions define disability from a functional perspective and are collectively a meaningful measure of disability for data collection and reporting.</p> <p>Edits initially proposed by ACL utilize five of the six BRFSS questions specific to disability status (hearing, vision, mobility, self-care, and independent living). ACL will add the question related to cognition (Because of a</p>

	that suggested using the Behavior Risk Factor Surveillance System (BRFSS) questions to assess disability.	physical, mental, or emotional condition, do you have difficulty concentrating, remembering, or making decisions?).
Confidence Managing Chronic Conditions	<p>Suggestion to revise wording in Question #17 (How confident are you that you can manage your chronic conditions?) to reference both physical and emotional concerns.</p> <p>Positive comment received regarding inclusion of question at post-test (Question #2) to assist with evaluating change over time.</p>	ACL appreciates this comment and proposes revising the language to read, “How sure are you that you can manage your condition so you can do the things you need and want to do?” to be inclusive of both physical and emotional health concerns.
Health Status	<p>Specific to post-test Question #1 (In general, would you say that your health is...), comment that this question seems unnecessary unless the underlying assumption is that CDSME changes self-perceived health.</p> <p>Positive comment received regarding inclusion of self-rated health at post-test (Question #1) to assist with evaluating change over time.</p>	ACL is interested in utilizing this question to assess changes in self-rated health at pre/post intervention. If changes are not detected, we will consider removal of this item during the next data collection renewal.
Satisfaction Question	Request to add satisfaction question back into the post-survey.	A satisfaction question has not been part of the required data collection elements, though some grantees choose to collect this information voluntarily.
Additional Questions	Suggestion to incorporate questions specific to formal referral by	ACL appreciates the suggestion to collect more data but has decided in the interest of balancing data collection and burden to not include additional elements on the survey.

	physician, weight, exercise, medications, and health care utilization.	
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Program Information Cover Sheet

Topic/Issue	Comment	ACL Response
Funding Source	<p>Specific to Question #7, program facilitators may not know the funding source (determined by other program staff).</p> <p>Another comment was received suggesting that ACL clarify that the intent of question is to capture direct sources of funding support (vs. indirect/global support).</p> <p>Another comment was received that it would be helpful to have a description of funding sources.</p>	<p>ACL suggests that local program coordinators complete this question prior to submitting form for data entry.</p> <p>ACL will incorporate this revision.</p> <p>ACL will work with the National CDSME Resource Center to develop a brief overview of the various funding sources listed. Grantee can distribute this information to their partners.</p>
National Resource Center and National Database Language	Suggestion to use a term other than “chronic disease”, as there are many programs in the menu of health promotion programs.	ACL awarded a five-year cooperative agreement in 2016 that specifically designates a National Chronic Disease Self-Management Education (CDSME) Resource Center. This resource center houses the National CDSME Database. ACL may consider modifying the name of the National CDSME Resource Center if/when it is re-competed in 2021; however, such a change is not appropriate at this time.
Consent to Receive Information from National CDSME Resources Center	A comment was received that the addition of this question seems unnecessary to have as a standard question, since it should only be asked once of each leader. A suggestion was	Requesting this consent through a standard data collection form is the most direct manner ACL can use to ensure that program facilitators can opt in to receiving technical assistance

	made to ask this question at leader trainings instead.	communications from our National CDSME Resource Center. ACL is unable to require grantees to share information collected via facilitator trainings.
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Attendance Log

Topic/Issue	Comment	ACL Response
Format	Suggestion to modify format from portrait to landscape to accommodate participant signature.	Participant signatures are not required by ACL with respect to this data collection effort (and ACL does not retain the names of CDSME participants). If other partners/funders require participant signature, grantee should modify the format accordingly.
Program Name	Suggestion to add program name to form	The very top of the form has an editable field (Your Program Name) that can be customized by the grantee.
Participant Phone/Email Address	Suggestion to collect participant phone number and email address for facilitators to use for reminder follow-up.	ACL does not collect any personally identifiable information from participants. Grantees can independently request this information from participants as needed for programmatic reminders.

9. Explanation of any Payment or Gift to Respondents

Not applicable. There will be no payments or gifts to the respondents.

10. Assurance of Confidentiality Provided to Respondents

Personally identifiable information is not collected as part of this information collection; therefore, there are no assurances of confidentiality. However, individuals and organizations receive assurances for their responses under Section 934(c) of the Public Health Service Act,

42 USC 299c-3(c). Assurances under the PHSA provide respondents with the purposes for which the information is collected and that, in accordance with this statute, information about them is not used or disclosed for any other purpose. Using a standardized script, workshop leaders inform respondents that their responses on the Participant Information Survey will be kept private and used only for statistical purposes. Both the assurances and PRA public burden statement disclose that the survey participation is voluntary.

11. Justification for Sensitive Questions

The Participant Information Survey requests level of disability, type of chronic condition, and demographic characteristics including race and living status. These data will be used to determine the extent to which grantees are serving the intended populations. All data will be protected to the fullest extent possible by using an encrypted, secure cloud-based system.

12. Estimates of Annualized Burden Hours and Costs

12A. Estimated Annualized Burden Hours

Grantee staff

The expected burden on the data entry staff (estimation of 65 total data entry staff across 29 grantees) is 0.17 hours per workshop with a total burden of 229.5 hours (1,350 workshops x 0.17 hours per workshop) to enter information from the Program Information Cover Sheet, Attendance Log, and Participant Information Survey into the national database.

Local staff and volunteers

The CDSME grantees are expected to offer approximately 1,350 programs annually. ACL anticipates that one leader/delivery personnel at each of the programs will assume primary responsibility for the data collection tasks. The expected burden on the program facilitators is .33 hours per workshop with a total burden of 445.5 hours (1,350 workshops x .33 hours) to complete the Program Information Cover Sheet, record attendance on the Attendance Log and collect the Participant Information Survey.

Participants

It is anticipated that the ACL grantees (29 total across cohorts funded in FY 2017, FY 2018, and FY 2020) will reach about 13,500 program participants annually. Participants will be asked to complete the Participant Information Survey on a voluntary basis before or at the beginning of the first program session and to answer three questions at the last session. The estimated burden on each participant is 0.20 hours, totaling 2,700 hours.

Total Burden Hours

ACL estimates that the total number of burden hours for grantee staff, local staff and volunteers, and program participants is 3,375 hours. The burden hours per form and respondent are summarized in Exhibit 1:

Exhibit 1: Estimated annualized burden hours

ACL estimates the burden associated with this **collection of information** as follows:

Respondent/Data Collection Activity	Number of Respondents	Responses Per Respondent	Hours Per Response	Annual Burden Hours
Program facilitators (Program Information Cover Sheet, Attendance Log)	1,350	Once per program	.33	445.5
Program participants (Participant Information Survey)	13,500	1	.20	2,700
Data entry staff (Program Information Cover Sheet, Attendance Log, Participant Information Survey)	65	Once per program times 1,350 programs	.17	229.5
Total:				3,375

12B. Costs to Respondents

The annualized cost burden for respondents is estimated to be \$17,141. Exhibit 2 shows the estimated annual cost burden to each type of respondent, based on their time to complete the data collection tools. The hourly rate for the state staff, leaders, and data entry personnel based upon the average wages of similar professions published by the Department of Labor, Bureau of Labor Statistics. The hourly rate for the participants based on average Social Security monthly benefits. We are adjusting our hourly wage estimates by a factor of 100%.

This is necessarily a rough adjustment, both because fringe benefits and overhead costs vary significantly from employer to employer, and because methods of estimating these costs vary widely from study to study. Nonetheless, there is no practical alternative and we believe that doubling the hourly wage to estimate total cost is a reasonably accurate estimation method.

Exhibit 2: Estimated annualized cost burden

	Time Per Response	Annual Hour Burden	Cost Per Response	Annual Cost Burden
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Reporting (Program Participants)	.20	2,700	\$3.48 ¹	\$9,396
Reporting (Program Facilitators)	.33	446	\$14.60 ²	\$6,512
Record Keeping (Data Entry)	.17	230	\$5.36 ³	\$1,233
Third Party Disclosure	NA	NA	NA	NA
Total	.70	3,376	\$23.44	\$17,141

13. Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers

There are no other costs to respondents or record-keepers or capital costs.

14. Annualized Cost to the Federal Government

AoA Project Officers will review individual and aggregate data to track grantee progress toward goals, as well as identify opportunities for both targeted and broad-based technical assistance. The total Federal staff burden hours spent reviewing and analyzing the program data are estimated to be 150 hours annually at an average salary rate of \$58.61 per hour for a total of \$8,792. In addition, AoA awards a cooperative agreement to the National CDSME Resource Center with dedicated funds to support and manage the national database.

Federal staff oversight	\$10,990 ⁴
Cooperative agreement funds	\$227,336
TOTAL:	\$238,326

15. Explanation for Program Changes or Adjustments

There is an adjustment increase of 10,283 respondents and a program change increase of 2,789 annual burden hours. ACL is not requesting renewal of Host/Implementation Organization Information Form or performance report instructions. ACL intends to continue using an online data entry system for the program and participant survey data. In addition to non-substantive formatting edits, minor changes were made to the program information cover sheet and

1 Social Security Administration, Social Security Monthly Statistical Snapshot, July 2019.

https://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/

2 US Department of Labor, Bureau of Labor Statistics, Occupational Outlook Handbook, Health Educators and Community Health Workers. <https://www.bls.gov/ooh/community-and-social-service/health-educators.htm>

3 US Department of Labor, Bureau of Labor Statistics, Occupational Outlook Handbook, General Office Clerks. <https://www.bls.gov/ooh/office-and-administrative-support/general-office-clerks.htm>

4 Federal staff costs based on 2019 hourly wage rate of \$58.61 for a Project Officer at the GS 13-8 level <https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/salary-tables/pdf/2019/DCB.pdf>. A factor of 25%, or \$2,198, has been added to the base of \$8,792 to account for benefits.

participant information survey. All changes proposed are based on feedback from a focus group that included a sub-set of current grantees, as well as consultation with subject matter experts.

- Program Information Cover Sheet:
 1. Question #2: Added consent on behalf of the program facilitators to receive program updates/information from the National CDSME Resource Center.
 2. Question #5: Additional evidence-based CDSME programs added to the list (reflective of approved programs included in the FY2019 Funding Opportunity Announcement).
 3. Question #7: Information regarding funding source(s) requested to assess progress toward developing a sustainable program delivery infrastructure that is not solely reliant on ACL discretionary dollars.

- Participant Information Survey:
 1. Participant I.D. modified to reduce risk of personally identifiable information exposure.
 2. Question #10: Added question regarding veteran status to further describe program participants, as well as to assist with partnerships with veteran-serving organizations.
 3. Question #14: Anxiety Disorder and Depression are listed separately (vs. being combined). Also included Yes/No response options for each chronic condition listed to improve data analyses and reporting.
 4. Question #15: Response options have been delineated as sub-bullets (vs. being grouped into a single item) to align with the American Community Survey.
 5. Question #16: Added question regarding social isolation, a construct that has been demonstrated to have an association with health-related risks for older adults. This question will also be asked upon completion of the last program session.
 6. Question #17: This question will be asked at baseline and upon completion of the last program session to measure change.

16. Plans for Tabulation and Publication and Project Time Schedule

Data will be due semi-annually at minimum to align with required reporting periods (though encouraged more frequently to allow for real-time monitoring) and reviewed by AoA project officers and technical assistance liaisons at the National CDSME Resource Center. Data will be aggregated and analyzed by AoA and NCOA on a quarterly basis, and posted on the National CDSME Resource Center website in the format of program highlights and charts. NCOA will provide AoA and our grantees access to the data in charts, graphs, and other summaries depicting the national data and each state's data.

17. Reason(s) Display of OMB Expiration Date is Inappropriate

The OMB expiration date will be displayed on all data collection instruments.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification.