**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 2015 Prevention and Public Health Funds (PPHF-2015), ACL awarded 8 cooperative agreements for a 2-year project period beginning September 1, 2015.

Grantee agencies represent a variety of organization types, including state agencies (aging and public health), area agencies on aging, universities, nonprofit organizations, and tribes. 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 Stanford University [Chronic Disease Self-Management Program (CDSMP)](http://patienteducation.stanford.edu/programs/cdsmp.html). In addition to [the English version of the Stanford CDSMP](http://www.aoa.gov/AoARoot/Site_Utilities/Standard_External_Disclaimer.aspx?redirection=http://patienteducation.stanford.edu/programs/cdsmp.html), which is appropriate for any type of chronic condition, other evidence-based self-management education programs have been developed at Stanford University 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, site 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 which 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 TA needs.

Legal and Administrative Requirements

The statutory authority for cooperative agreements under the Prevention and Public Health Fund program announcement is contained in the Consolidated Appropriations Act, 2016, Pub. L. 114-113, Div. H., Title II; 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).

This data collection is authorized under Section 301 of the Public Health Service Act (42 U.S.C. 241) and Section 202 of the Older Americans Act (Public Law 109-365, Title II, Section 202) and required by the Prevention and Public Health Fund which requires:

a) The Secretary shall establish a publicly accessible website to provide information regarding the uses of funds made available under section 4002 of Public Law 111-148; and 220 b (5) Semi-annual reports from each entity awarded a grant, cooperative agreement, or contract from such funds with a value of $25,000 or more, summarizing the activities undertaken and identifying any sub-grants or sub-contracts awarded (including the purpose of the award and the identity of the recipient), to be posted not later than 30 days after the end of each 6-month period.

In addition, it is expected that any grants financed by the PPHF will be accompanied by a high level of transparency, oversight, and accountability. In April 2012, the U.S. Health and Human Services (HHS) Division of Grants released an Action Transmittal: FY2012 Appropriations Act Guidance for the HHS Grants Community noting that all recipients of PPHF must follow HHS guidance related to the tracking, monitoring and reporting on the use of PPHF financing. AoA has outlined basic requirements for reporting in the CDSME Program Announcement and in the Standard Terms and Conditions of grantees’ notice of awards. These notices require each grantee to prepare and submit progress reports to AoA that will enable the agency to monitor program performance.

1. **Purpose and Use of the Information Collection**

AoA will use the information from the PPHF 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 PPHF CDSME grantee progress.

Information from the PPHF 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 of PPHF CDSMP grantees. The following types of tools included in the collection and purposes of each are:

* **Semi-Annual Performance Report Directions and Sample Template** will be provided to grantees to offer additional clarification regarding the performance reporting template and the type of information that grantees should include in the various sections of the report to ensure efficient, accurate, and comprehensive reporting.
* An **Organization Information Form** will be completed by a staff person at each new organization hosting and implementing workshops. Basic information, including the name, location, and type of agency will be obtained and then entered into a national CDSME database. AoA will use this data on program locations to map the delivery infrastructure, identify types of agencies involved in program delivery, and to monitor changes in delivery capacity.
* 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 4 out of the 6 workshop sessions (for those interventions with a finite end date), the recommended intervention dose.
  + A **Participant Information Survey** which under the previous OMB PRA clearance was completed by each participant on a voluntary basis, will now, per OMB guidance, be completed by a sample of participants. This tool documents 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 as a result of similar data collection efforts are available at:

<http://www.aoa.gov/AoARoot/AoA_Programs/HPW/ARRA/>

<https://www.ncoa.org/center-for-healthy-aging/cdsme-resource-center/>

1. **Use of Improved Information Technology and Burden Reduction**

The proposed PPHF 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.

1. **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.

1. **Impact on Small Businesses or Other Small Entities**

No small businesses will be involved in this study.

1. **Consequences of Collecting the Information Less Frequently**

CDSME grantees will submit data semi-annually. To meet the statutory requirements and execute program management functions, availability of timely data is critical. The project period for current grantees is 24 months. If data was only submitted annually or once throughout the project period, 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.). In addition, it is anticipated that AoA will need to respond to frequent status reports about the use of Prevention and Public Health Funds.

1. **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.

1. **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 March 7, 2016, Volume 81, Number 44, page 11803. No public comments were received.

AoA encouraged current and former PPHF grantees to respond to the Federal Register notice through a reminder sent out to grantee point of contacts.

In addition to internal feedback solicited from colleagues within ACL’s Center for Policy and Evaluation, input was also gathered from the Centers for Disease Control and Prevention Arthritis Program (with a particular emphasis on the collection of participant information), CDSME and self-management support program developers/administrators (with a particular emphasis on the collection of workshop information), and current users of the CDSME National Database.

1. **Explanation of any Payment or Gift to Respondents**

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

1. **Assurance of Confidentiality Provided to Respondents**

Individuals and organizations will be assured of the confidentiality of their responses under Section 934(c) of the Public Health Service Act, 42 USC 299c-3(c). They will be told the purposes for which the information is collected and that, in accordance with this statute, any identifiable information about them will not be used or disclosed for any other purpose. Respondents will be informed by workshop leaders using a standardized script that their responses on the Participant Information Survey will be kept private and used only for statistical purposes and that participation in the survey is voluntary. Identifying information such as name, zip code, birth date, etc. is not being collected as part of this effort.

1. **Justification for Sensitive Questions**

This project includes questions that may be considered sensitive. The revised 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 both determine the extent to which grantees are serving the intended populations. All data will be protected to the fullest extent possible by using encrypted, password protected data files.

1. **Estimates of Annualized Burden Hours and Costs**

***12A. Estimated Annualized Burden Hours***

This project will use a sampling approach to data collection. To calculate the sample size, the projected number of workshops (3,642, based on grantee projections) was entered into a sample size calculator available at <http://www.aoa.acl.gov/Program_Results/POMP/Calculator.aspx>. Additionally, all projected workshops offered by tribal partners are included, as this is a specific group that will be oversampled. Based on the calculations, the necessary sample size at the workshop level is 386. Since the sample was calculated at the workshop level, we multiplied the average number of participants per workshops (which is 12) to arrive at the number of participants we expect to survey (386 workshops x 12 participants per workshop = 4,632 participants).

***Grantee project staff***

There are currently 8 PPHF CDSME grantees. ACL estimates that 8 lead project staff (one from each funded grantee) will submit the required semi-annual progress reports. On average, the estimated burden is 8 hours per semi-annual report or 16 hours annually, totally about 128 annual burden hours for grantee staff.

***Local staff and volunteers***

The PPHF CDSME grantees are expected to offer approximately 3,642 programs annually. ACL anticipates that one leader/delivery personnel at each of the programs will handle the data collection tasks. These programs will be sponsored by approximately 80 host organizations. A local staff person at each new host organization will complete a host organization form. On average, each of the funded grantees will have 2 data entry staff for a total of 16.

The expected burden on the 16 data entry staff is 0.30 hours per workshop with a total burden of 116 hours (386 workshops x 0.30 hours per workshop) to complete the Program Information Cover Sheet, record attendance on the Attendance Log and collect the Participant Information Survey.

Local organization staff will complete the Organization Information Form. Their expected burden is .05 hours per form x 80 organizations or a total annual burden of 4 hours. A staff person with the CDSME National Resource Center will enter data from the Organization Information Forms. The costs of this person’s time are included within the budget of their cooperative agreement and are therefore not included in the estimates of Total Burden Hours.

***Participants***

It is anticipated that the ACL grantees (FY 2015 and FY 2016) will reach about 43,700 program participants over the course of their project periods. Assuming a sampling versus census approach, 4,632 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 one question at the last session. The estimated burden on each participant is 0.10 hours, totaling 463 hours.

***Total Burden Hours***

ACL estimates that the total number of burden hours for grantee staff, local staff and volunteers, and program participants is 827 hours. The burden hours per form and respondent are summarized in Exhibit 1:

**Exhibit 1: Estimated annualized burden hours**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Type of**  **Respondent** | **Form**  **Name** | **Estimated Number of**  **Respondents** | **Number of Responses Per Respondent** | **Average**  **Time per Response**  **(in hours)** | **Total Burden Hours (Annual)** |
| Project staff | Semi-annual Performance Report | 8 | Twice a year | 8 | 128 hours |
| *Total project staff burden hours: 128* | | | | | |
| Local agency leaders/delivery personnel | Program Information Cover Sheet / Participant  Information Survey/ Attendance Log | 386 delivery personnel | One set per program x 386 programs | .30 | 116 hours |
| Local data entry staff | 16 data entry staff | Once per program x 386 programs | .30 | 116 hours |
| Local organization staff | Host Organization Data Form | 80 staff | 1 | .05 | 4 hours |
| Database data entry staff | CDSME National Resource Center Staff\* | 80 forms\* | .05\* | 4 hours\* |
| *Total local personnel burden hours: 120 leader/local staff reporting hours + 116 data entry hours = 236*  *\*The 4 hours for the database data entry staff is included in the CDSME National Resource Center Cooperative Agreement and is not included in the Total Burden Hours* | | | | | |
| Program participants | Participant  Information Form | 4,632 | Once | .10 | 463 hours |
| *Total burden hours for all state and local respondents: 827 (plus 4 hours for CDSME National Resource Center staff)* | | | | | |

***12B. Costs to Respondents***

The annualized cost burden for respondents is estimated to be $13,246. 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 was based upon the average wages of similar professions published by the Department of Labor, Bureau of Labor Statistics. The hourly rate for the participants was 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**

| **Type of Respondent** | **Total Burden Hours** | **Hourly Wage Rate** | **Total Annual Cost Per Respondent** |
| --- | --- | --- | --- |
| Grantee Staff | 128 | $90.86[[1]](#footnote-1) | $11,630 |
| Local Delivery Personnel | 116 | $42.16[[2]](#footnote-2) | $4,890 |
| Local Data Entry Staff | 120 | $28.32[[3]](#footnote-3) | $3,398 |
| Participants | 463 | $14.20[[4]](#footnote-4) | $6,574 |
| *Total Costs to Respondents: $26,492* | | | |

1. **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.

1. **Annualized Cost to the Federal Government**

AoA Project Officers will review the semi-annual reports and national compiled data. 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 $50.04 per hour for a total of $7,506.00. In addition, AoA awards a cooperative agreement to NCOA to manage the database.

Federal staff oversight $9,383[[5]](#footnote-5)

Annual Contract $89, 653[[6]](#footnote-6)

***TOTAL:*** ***$97,159***

1. **Explanation for Program Changes or Adjustments**

Based on feedback from internal and external stakeholders, modifications to the data collection materials were made. Consistent with the approved ACL Falls Prevention information collection request (OMB Control No. 0985-0039, Exp. Date 01/31/2018), sensitive information was removed/modified from the Participant Information Survey, including:

* Change in name to participant ID
* Change from full birth date to age
* Deletion of participant zip code
* Changed wording of gender question

Other changes on the Participant Information Survey include:

* Changes in list of chronic conditions to reflect current target populations and prior data results (addition of kidney disease, obesity, and schizophrenia; deletion of Alzheimer’s and multiple sclerosis)
* Specific to disability category, deletion of Behavioral Risk Factor Surveillance System question and replacement with American Community Survey questions to obtain more specific information
* Addition of a question about health status (self-rated health as excellent, very good, good, fair, or poor) to get a clearer profile of the participants to identify vulnerability of population served, as well as share with potential program funders
* Addition of question about provider referral to monitor the success of increased efforts to engage health care systems to refer to community programs
* Addition of question about self-efficacy to be completed at last program session to be used as an outcome performance monitoring indicator

Minor changes are also proposed in the Program Information Cover Sheet, Organization Form, Attendance Form and Semi-Annual Progress Report to make them more consistent with changes in grant expectations outlined in the more recent funding opportunity announcements, particularly the addition of new one-on-one programs which made parts of the forms, geared to group programs, no longer relevant. Changes include:

* Listing additional CDSME and self-management support programs on the Program Information Cover Sheet (e.g. EnhanceWellness, HomeMeds, PEARLS)
* Deleting staff/volunteer status from the Program Information Cover Sheet, and adding email address to the program facilitator contact information.
* Combing the organizational information form for host organizations and implementation sites to simplify collection of this information.

ACL will not be requesting renewal for the **Integrated Services Delivery System Assessment Tool** asthis information is not relevant for monitoring the new grants.

In addition to changes in the forms, based on guidance from OMB, the program will start collecting individual-level data from a sample of program participants rather than from a census as was approved previously. The benefit of using a sample is the reduced burden on the public. But this approach will place an increased burden on participating sites and Federal staff. As there is no contract in place for sampling or data collection with the CDSME grantees, the providers themselves, with the support of Federal staff and the TA provider for this program, will have to generate and implement an acceptable sampling frame.

1. **Plans for Tabulation and Publication and Project Time Schedule**

Data will be due semi-annually and reviewed by AoA project officers and technical assistance liaisons at the CDSME National Resource Center. If inconsistencies are noted, states will be asked to correct and resubmit their reports. Once all reports are verified, the data will be aggregated and analyzed by AoA and NCOA. Based on previous data collections, this process will take about one month after each progress report. When the national data is finalized, the aggregate information will be posted on the AoA and NCOA websites, which are both available to the public. NCOA will provide AoA and state grantees access to the data in charts, graphs, and other summaries depicting the national data and each state’s data. A report, summarizing the findings and lessons learned, will be prepared no later than 6 months after each data submission.

.

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

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

1. **Exceptions to Certification for Paperwork Reduction Act Submissions**

There are no exceptions to the certification.

1. Bureau of Labor Statistics, US Department of Labor, Occupational Outlook Handbook, 2016-17 Edition, Medical and Health Services Managers, <http://www.bls.gov/ooh/management/medical-and-health-services-managers.htm>

   Accessed May 23, 2016. [↑](#footnote-ref-1)
2. Bureau of Labor Statistics, U.S. Department of Labor, Occupational Outlook Handbook, 2016-17 Edition, Health Educators and Community Health Workers, <http://www.bls.gov/ooh/community-and-social-service/health-educators.htm> Accessed May 23, 2016. [↑](#footnote-ref-2)
3. Bureau of Labor Statistics, US Department of Labor, Occupational Employment Statistics, Occupational Employment and Wages, Data Entry Keyers, <http://www.bls.gov/oes/current/oes439021.htm>

   accessed May 23, 2016. [↑](#footnote-ref-3)
4. Social Security Administration, Social Security Monthly Statistical Snapshot, March 2016. <http://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/> accessed May 23, 2016. [↑](#footnote-ref-4)
5. Federal staff costs based on 2016 hourly wage rate of $50.04 for a Project Officer at the GS 13-5 level <https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/salary-tables/16Tables/html/DCB_h.aspx> Accessed May 23, 2016. A factor of 25%, or $1,877, has been added to the base of $7,506 to account for benefits. [↑](#footnote-ref-5)
6. NCOA provided this estimate which includes actual database costs, software licensing, training webinars, and personnel costs for database maintenance, compiling reports, data analysis and training [↑](#footnote-ref-6)