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

A. Justification

1. Circumstances Making the Collection of Data Necessary

<u>Background</u>

This is a new Information Collection Request (ICR).

The Administration on Aging (AoA), now part of the Administration for Community Living (ACL), will use the proposed set of data collection tools to monitor grantees receiving cooperative agreements in response to the funding opportunity: "Empowering Older Adults and Adults with Disabilities through Chronic Disease Self-Management Education (CDSME) Programs financed by 2012 Prevention and Public Health Funds (PPHF-2012)." ACL awarded 22 cooperative agreements for a 3-year project period beginning September 1, 2012.

This data collection is necessary for uniform monitoring of CDSME grantees and to improve reporting 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 Consolidated Appropriations Act, Fiscal Year 2012, Public Law 112-74, Title II, Section 220. The proposed data collection will also allow for a possible future analysis of Medicare claims data and health care utilization for the purpose of determining if program participation is related to changes in health care utilization and /or health care costs.

The most widely disseminated CDSME is the Stanford University Chronic Disease Self-Management Program (CDSMP). The Stanford program teaches participants the skills to manage their conditions, build their self-confidence, adopt healthy behaviors, and enhance their quality of life. The program consists of workshops conducted once a week for six weeks in community-based settings such as senior centers, congregate meal sites, faith-based organizations, libraries and senior housing programs. People with different chronic health conditions attend together, and the workshops are led by a pair of trained facilitators, many of whom are lay persons with chronic conditions.

In addition to the English version of the Stanford CDSMP, 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 arthritis, diabetes, chronic pain, or HIV, for Spanish-speaking individuals, and in an internet format.

AoA has a long history of supporting CDSME programs and other evidence-based health

programs. Since 2003, AoA, in conjunction with the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Medicare and Medicaid Services (CMS) and other Department of Health and Human Services (HHS) and private sector partners, has funded collaborations between the aging and public health networks at the state and community level.

Two core AoA grant programs that have supported CDSME programs are the Evidence-Based Disease and Disability Prevention Program (EBDDP) and the American Recovery and Reinvestment Act of 2010 Communities Putting Prevention to Work: Chronic Disease Self-Management Program (Recovery Act CDSMP). Through the latter initiative, in March 2010 AoA awarded 2-year cooperative agreements to 47 states and territories. These projects had two major goals: (1) to deliver evidence-based self-management programs to 50,000 older adults with chronic conditions who completed at least four of the six workshop sessions and (2) to strengthen and significantly expand the capacity of the public health and aging networks through distribution and delivery systems that increase the availability of, and access to, these programs.

AoA also funded a National Resource Center to provide technical assistance (TA) to the EBDDP and Recovery Act CDSMP grantees. The Resource Center created an online, web-based data collection system which states and program sites used to provide data on their workshops. This system allowed 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. The online system also allowed AoA to quickly respond to frequent requests for information on the Recovery Act grantee performance.

Most Recovery Act CDSMP grantees have voluntarily continued to use the online database to report their progress. As of January 2013, the grantees had reported hosting 11,177 CDSMP workshops at 6,778 unique implementation sites, reaching 126,485 participants, with 94,270 completing at least four of six sessions. More than 61% of participants reporting relevant data indicated having multiple chronic conditions, with the most common conditions being hypertension (43.9%), arthritis (41.3%), and diabetes (31.4%). The average age of a CDSMP participant is 66 years.

Legal and Administrative Requirements

The statutory authority for cooperative agreements under the PPHF program announcement is contained in Section 1701 (a)(3)(A-B), Section 1701(a)(4), and Section 1703(a)(4) of the Public Health Service Act; the Consolidated Appropriations Act, Fiscal Year 2012, Public Law 112-74; and the Patient Protection and Affordable Care Act, Public Law 111-148; and Title IV, Section 4002 of the Affordable Care Act (PPHF).

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 Consolidated Appropriations Act, Fiscal Year 2012, Public Law 112-74, Title II, Section 220.

> Under Section 220 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.

2. <u>Purpose and Use of the Information Collection</u>

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 possible impact on health care and health care utilization,
6) 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
7) Provide information for reports to Congress, other governmental agencies, stakeholders and to the public about PPHF CDSME grantee progress.

Similar information obtained from the Recovery Act CDSMP grantees was shared on a monthly basis in ACL Dashboard Reports and for Centers on Disease Control and Prevention ARRA Communities Putting Prevention to Work reports. Periodic reports were also provided in response to the U.S. Health and Human Services Multiple Chronic Conditions

Strategic Framework Initiative. It is anticipated that similar types of reports will be requested for grants financed through the Prevention and Public Health Fund.

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 the National Resource Center technical assistance website.

AoA proposes to adapt tools successfully used to monitor the progress of AoA's Recovery Act CDSMP grantees. The types of tools and purposes of each include:

- **Semi-annual progress reports** will be completed by the state lead staff and submitted to AoA by email. These reports enable AoA to monitor grantee performance, identify program implementation issues and possible technical assistance needs, as well as successes and best practices. The standardized format will facilitate uniform data collection and easier compilation of reports. The proposed report uses the same format as that described in the "Guidelines for Preparing Performance Reports for Discretionary Grants Supported by the U.S. Administration for Community Living" which has OMB Approval No. 0985-0006 (Expiration: 12/31/2015). Based on these guidelines, we have prepared a set of instructions to provide sample responses on the approved template.
- An **Integrated Services Delivery System Assessment Tool** will be completed by state lead staff once a year through an online survey format. This information will be used by AoA to determine grantee's progress in developing sustainable program delivery systems and to identify model state approaches and best practices.
- An **Organization Data** form will be completed by the data entry staff whenever a new workshop site is recruited. Basic information including the name and location are recorded on an Excel spreadsheet and then emailed to the National Resource Center for entry into the online database. AoA uses this data on workshop locations to map the delivery infrastructure, identify types of agencies involved in program delivery, and to monitor the increase in delivery capacity.
- Workshop Data Collection Tools are paper tools used to collect information at each workshop:
    - o A **Workshop Information Cover Sheet** and an **Attendance Log** are completed by the leaders. 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.
    - o A **Participant Information Survey** is completed by each participant on a voluntary basis. This tool documents participants' demographic and health characteristics, including date of birth, sex, race/ ethnicity, zip code, types of chronic conditions, disability status, whether they are a caregiver, and education level.

At the end of each workshop, local data entry staff or volunteers will enter information from the Workshop Information Cover Sheet and Participant Information Surveys into the national online 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/

http://www.ncoa.org/improve-health/center-for-healthy-aging/chronic-disease-1.html

3. **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 by the Recovery Act CDSMP grantees. The existing national database is maintained by a National Resource Center funded by AoA. 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. The Resource Center 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 study.

6. **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 36 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.

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 23, 2012, Volume 77, Number 141, page 43092. Four sets of comments were received. Most of the comments focused on the sensitive nature and the wording of some questions. AoA has addressed these comments by revising the data collection tools and procedures. AoA received one non-germane comment discussing concerns about general government spending. As this comment was not related to the content of the Federal Register notice, AoA is not able to substantively address the commenter's concerns. The complete set of comments with responses is available at:
http://www.aoa.gov/AoARoot/AoA_Programs/Tools_Resources/collection_tools.aspx

AoA encouraged former AoA Recovery Act grantees to respond to the Federal Register notice through two reminders sent out to grantee point of contacts.

In addition, this project builds upon a collaborative "Health Program Registration System" project with the Centers for Medicare & Medicaid Services (CMS) designed to develop and test a registration system for Medicare beneficiaries that complete a chronic disease self-management program (CDSMP) and measure the impact of CDSMPs on health care utilization using Medicare claims data. This project, conducted by The MITRE Corporation in 2011, documented the data requirements, privacy protections and operational considerations needed to create the basis for analyzing Medicare beneficiary claims data. More recently, CMS has been conducting a large retrospective analysis of community-based prevention and wellness programs authorized by the Affordable Care Act, Title IV, Subtitle C, Section 4202. Part of this project included matching some Chronic Disease Self-Management Program participant data with Medicare claims data using zip codes, birthdates and gender.

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

We will comply with Section 934(c) of the Public Health Service Act, 42 USC 299c-3(c). All participants will be asked to read and sign an IRB-approved Participant Consent Form to assure them of the confidentiality of their responses. 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 also be informed by workshop leaders using a standardized script that their responses on the Participant Information Survey will be kept private and that participation in the survey is voluntary. Identifying information such as zip codes, birth date and gender will be stored in

a secure database maintained by a national resource center that is very experienced in collecting and handling secure data.

11. **Justification for Sensitive Questions**

This project includes questions that may be considered sensitive. The Participant Information Survey requests participants' zip codes, birthdate, gender, 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 as well as to allow for a possible future analysis of Medicare claims data and health care utilization. All data will be protected to the fullest extent possible by using encrypted, password protected data files.

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

12A. Estimated Annualized Burden Hours

State staff level
There are 22 PPHF CDSME grantees. AoA estimates that 22 state department staff (one from each funded state) will submit the required Semi-annual progress reports and the Annual Integrated Services Delivery System Assessment Tool. On average, the estimated burden is 8 hours per semi-annual report and 4 hours for the annual systems assessment, for a total of 440 annual burden hours for state staff.

Local staff and volunteers
The PPHF CDSME grantees will conduct approximately 2000 workshops. AoA anticipates that one leader at each of these workshops will handle the data collection tasks and that on average, each of the funded states will have 3 data entry persons for a total of 66.

The expected burden on the 2000 leaders is 0.25 hours per workshop (with a total burden of 500 hours) to complete the Workshop Information Form, record attendance on the attendance log and collect the Participant Information Forms.

The 66 data entry staff are expected to each complete about 15 Organization Data Forms on 990 new locations with an average burden of .05 hours per location (for a total of about 50 hours). They will also enter data from approximately 2000 workshops including the Workshop Information Forms and Participant Information Surveys, with an average burden of 0.25 hours per workshop or a total of 500 hours. Therefore the estimated annual burden on data entry staff to complete both the Organizational Information Form and enter data on the workshop forms totals about 550 hours.

Participants
It is anticipated that the AoA grantees will reach about 25,000 workshop participants annually. Each participant will be asked to complete the Participant Information Survey on a

voluntary basis before or at the beginning of the first workshop session. The estimated burden on each participant is 0.10 hours.

Total Burden Hours

AoA estimates that the total number of burden hours for state staff, local staff and volunteers and workshop participants is 3990 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)
State Government	CDSME Semi-annual Program Progress Report	22	Twice a year	8	352
	Integrated Services Delivery System Assessment Tool	22	Once annually	4	88
				Total state government burden hours: 440	
Local agency workshop leaders	Workshop Information Cover Sheet / Participant Information Survey/ Attendance Log	2000 leaders	Once per workshop x 2000 workshops	15/60 data collection	500 leader hours
Local data entry staff		66 data entry staff	Once per workshop x 2000 workshops	15/60 data entry	500 data entry hours
Local agency data entry staff	Organization Data Form	66 data entry staff	15 entries each	3/60	50 data entry hours
	Total local personnel burden hours: 500 leaders + 550 data entry hours = 1050				
Workshop Participants	Participant Information Survey	25,000	Once	6/60	2500
	Total burden hours for all respondents: 3990				

12B. Costs to Respondents

The annualized cost burden for respondents is estimated to be $44,092. 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.

Exhibit 2: Estimated annualized cost burden

Type of Respondent	Total Burden Hours	Hourly Wage Rate	Total Annual Cost Per Respondent
State Staff	440	$40.52[1]	$17,829
Local Leaders	500	$22.03[2]	$11,015
Local Data Entry Staff	550	$13.95[3]	$7,673
Participants	2500	$7.03[4]	$17,575
			Total Costs to Respondents: $44,092

13. <u>Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers</u>

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

14. <u>Annualized Cost to the Federal Government</u>

AoA Project Officers will review the semi-annual reports and annual Systems Assessment and national compiled data. The total Federal staff burden hours spent reviewing and analyzing the program data are estimated to be 175 hours annually at an average salary rate of $45.99 per hour for a total of $8048.00. In addition, AoA has been supporting a National Resource Center to manage the database.

Federal staff oversight $8,048[5]

Annual Contract $89, 653[6]

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1 Bureau of Labor Statistics, US Department of Labor, Occupational Outlook Handbook, 2012-13 Edition, Medical and Health Services Managers, http://www.bls.gov/ooh/management/medical-and-health-services-managers.htm
accessed June 25, 2012.

2 Bureau of Labor Statistics, U.S. Department of Labor, Occupational Outlook Handbook, 2012-13 Edition, Health Educators, http://www.bls.gov/ooh/community-and-social-service/health-educators.htm
Accessed June 25, 2012.

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#nat
accessed June 25, 2012

4 Social Security Administration, Social Security Monthly Statistical Snapshot, May 2012.
http://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/ accessed June 25, 2012

5 Federal staff costs based on 2012 hourly wage rate of $45.99 for a Project Officer at the GS 13-5 level
http://www.opm.gov/oca/12tables/html/gs_h.asp   Accessed June 25, 2012

6 The current Resource Center provided this estimate which includes actual database costs, software licensing,

TOTAL: $97,701

15. Explanation for Program Changes or Adjustments

Not applicable—this is a new information collection request.

16. Plans for Tabulation and Publication and Project Time Schedule

Data will be due semi-annually and reviewed by the National Resource Center state liaisons and the AoA project officers. If inconsistencies are noted states will be asked to correct and resubmit their reports. Once all reports are in and verified, the data will be aggregated and analyzed by the Resource Center and AoA. Based on previous data collections, this process will take about two months after each progress report. When the national data is finalized, the aggregate information will be posted on the Resource Center and AoA website, which are both available to the public. The Resource Center 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.

OMB approval for three (3) years is requested.

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

Not applicable. 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.

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training webinars, and personnel costs for database maintenance, compiling reports, data analysis and training