Optional Data Fields in the National CDSME Database

(as of May 16, 2019)

Data elements required by the Administration for Community Living (ACL) as part of your Prevention and Public Health Fund (PPHF) are included in the OMB-approved forms, available on the primary Data Entry, Collection, and Management Resources page, under ‘Data Collection Tools’.

If you are a former ACL grantee, a current or former CDC Arthritis grantee, or associated with any other organization tracking your program activity in the National CDSME Database, please be advised that data fields are updated in accordance with changes to ACL/PPHF requirements. The current forms expire on 10/31/2019. Typically, new forms are available on or around the expiration date. Please be sure that your network partners are using the most current forms.

In addition, NCOA’s Center for Healthy Aging (CHA) offers several optional fields in the database, which you can incorporate into your data collection tools. This sheet provides an overview of those optional items, recommended wording and other context.

These items marked as “(optional)” in the database and shown by their short name (highlighted in GREEN) next to the question for participant-level items. Optional items are often requested by database users or program leads through technical assistance calls, through annual database technical assistance surveys, or recommended by CHA staff to better monitor important programmatic changes and improve monitoring.

At this time, sensitive data, or data that can be used in combination with other fields to identify a person are not collected. This includes names, Medicare #’s, Social Security #’s, medical record #’s, participant-level Zip Codes, or Dates of Birth. Optional items are vetted by ACL.

Generally, because fields are often visible to all database users, we consider incorporating data fields that have the potential to benefit multiple grantees/networks. If you have a question that you would like to add to the optional data fields, please email the database manager at angelica.herrera-venson@ncoa.org. Items that may conflict with or are similar to existing ACL required questions/fields are typically rejected.

If you have any questions, please contact that database manager at angelica.herrera-venson@ncoa.org.
Health Insurance

The National CDSME Database has had an optional health insurance question for over a year. In August 2018, it will be updated with several changes, including a division between types of Medicare Advantage plans, employer-based plan, Indian Health Services, and clarification on Tricare and Veteran’s health system vs insurance.

The suggested phrasing for your data collection forms:

Which of the following best describes your health insurance coverage? (Please put “X” in all boxes that apply, e.g. ☒ [Health Insurance]

☐ Medicare (Original)
☐ Medicare Advantage Plan – (HMO, PPO, Fee-for-Service, Medical Savings Account) (Please specify: ________________)
☐ Medicare Advantage Plan – (Special Needs Plans including Dual-Eligible SNP) (Please specify: ________________)
☐ Medicaid
☐ Employer or Union-based Health Insurance
☐ Veteran’s Health Care Benefits/Coverage
☐ Veteran’s Health System
☐ TRICARE/ TRICARE for Life
☐ Indian Health Services
☐ No Insurance
☐ Other Private Insurance (Please specify): ______________________ (Please specify: ________________)

Why include this question: Identifying the health insurance coverage of participants of your program can lead to you using this information to improve your value proposition to health payors. Include this measure in your survey if you are interested in propositioning health payors to extend coverage to your evidence-based program(s) offered. Use this information to calculate return on investment and make your best pitch! See the Roadmap to Community-Integrated Health Care to learn more.
Living Arrangements

**Living Arrangements**: In addition to asking the binary question about whether a participant lives alone or with others, it may be a value add to capture a picture of their living arrangements, such as:

Which best describes your living arrangement? (check all that apply)
- □ With others (How many, including yourself? ___)
- □ Alone
- □ With adult children
- □ With other family or friends
- □ In a nursing home or residential facility
- □ Senior housing
- □ Incarcerated

**Why this matters**: Research has suggested that who you live with is just as important as the number of people you live with. In fact, overall well-being has been shown to vary based on living arrangement. Use this question to learn more about the participants you serve.

Well-Being

NCOA is encouraging the use of the 100MLives Aging Wellbeing Assessment with all of our partners to have a uniform measure of quality of life and identify promising programs and services across the aging services network. This question is well-validated and easily integrated into the surveys.

Imagine a ladder with steps numbered from zero at the bottom to 10 at the top. The top of the ladder represents the **best possible life for you** and the bottom of the ladder represents the **worst possible life for you**. On which step of the ladder would you say you personally feel you stand at this time?

<table>
<thead>
<tr>
<th>Worst Possible Life</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Best Possible Life</th>
</tr>
</thead>
</table>

**Why this matters**: Not only does this question provide a broad overview of the well-being of the individual participant, but it provides information on how the program may influence overall quality of life. Partners across the nation are integrating these questions into their metrics. Use this question to join others in assessing well-being across a common metric and to learn how your efforts are improving quality of life. Ask this question at both pre- and post-survey points.
**Monthly Household Income**

Beginning in August, 2018, the National CDSME Database will include an optional item on monthly household income. This question allows NCOA to better assess whether programs and services it supports are reaching vulnerable, low-income older adults. The narrow brackets (~$500) when coupled with the required question on ‘Living Alone (Y/N)’, can be used to estimate the individuals Federal Poverty Level.

The suggested phrasing for your data collection forms:

**Including yourself (and your spouse, if married), what is your combined monthly gross income now? (Consider all sources of income, including Social Security, pension, etc.)?** [Monthly Income]

- ☐ Less than $1,000
- ☐ $1,001 - $1,499
- ☐ $1,500 - $1,999
- ☐ $2,000 - $2,499
- ☐ $2,500 - $2,999
- ☐ $3,000 - $3,499
- ☐ $3,500 - $3,999
- ☐ $4,000 or more

**Why this matters:** Use this question if you are interested in who you are serving and who you are missing in terms of vulnerable, low-income older adults. This question can also add to identifying which programs are most appropriate for which population. Identifying the Federal Poverty Level is a powerful indicator of your impact on struggling segments of the older adult population.

**Alzheimer’s / Cognition**

Alzheimer’s disease was previously asked as a multiple-choice option, “Has a health care provider ever told you that you have any of the following chronic conditions?” This question was removed because few people responded in the affirmative (<1%). Systematics reviews in the U.S. and abroad have shown that anywhere from 50 to 90% of individuals with dementia are undiagnosed.⁠¹⁠ Coupled with the potential stigma and underdiagnoses of Alzheimer’s disease and dementias, the response rate to such a question is to be expected. Given the projections in the growth of Alzheimer’s disease and its impact on quality of life and mortality, there is continued interest in understanding the value of community-based interventions on persons with milder forms of dementia.

To capture Alzheimer’s disease or related disorders, dementia, or cognitive impairment, we offer a binary answer option (Yes or No) in the system, but the wording for this question is entirely up to you. Depending on your objective (measure actual diagnosis, assess cognitive impairment, or undiagnosed dementia), consider the following wording options, all of which can be answered by the program participant and does not require a caregiver or informant to respond on their behalf.

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¹ https://bmjopen.bmj.com/content/7/2/e011146#ref-4
OPTION 1: The following question on increased confusion or memory loss was added to the Behavioral Risk Factor Surveillance System (BRFSS) optional module in 2011, thus tested in the general population\(^2\) and has been recommended for use in Medicare’s Annual Wellness Visit.\(^3\)

*During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?* [Cognitive Impairment, Dementia, or Alzheimer’s Disease]

Yes or No

OPTION 2: The following question was shown to be sensitive enough to distinguish between demented and non-demented individuals, though its accuracy was greater in persons with mild dementia.\(^4\) There are some disadvantages of focusing exclusively on memory loss. Memory loss is a key symptom and important predictor and/or indicator of Alzheimer’s and related disorders; however, it is only one factor. Further, a recent study also found that a lack of awareness of that memory loss, also known as “anosognosia”, can itself be a predictor of the onset of mild cognitive impairment or Alzheimer’s disease 5 years later.\(^5\) Together with biophysical factors, a host of demographic and lifestyle behaviors may predict the onset of Alzheimer’s disease.\(^6\) Mild cognitive impairment does not always lead to Alzheimer’s disease.\(^7\)

*Are you having a problem with your memory?* [Cognitive Impairment, Dementia, or Alzheimer’s Disease]

Yes or No

OPTION 3: This question resembles the existing ACL form’s checklist of chronic conditions, in which Alzheimer’s Disease was removed. Given the underdiagnoses of the disease and stigma of disclosing a diagnosis, you are likely to get fewer positive responses. Moreover, individuals with a formal diagnosis may have greater cognitive impairment, which may prevent them, or their caregiver, from enrolling in the program.

*Has a health care provider ever told you that you have Alzheimer’s Disease or other related disorder?* [Cognitive Impairment, Dementia, or Alzheimer’s Disease]

Yes or No

**Satisfaction with Program**

Many organizations may be offering multiple programs, or just getting their programs off the ground. If you’re interested in measuring participants’ satisfaction and overall experience with the program, consider adding a satisfaction question or two. Response options are on a 5-point Likert scale. The suggested phrasing for your data collection forms for a general question around the quality of the program delivery:

*How would you rate your overall satisfaction with the quality of the program?* [Satisfaction with the Program]

Very Dissatisfied, Dissatisfied, Okay, Satisfied, Very Satisfied

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\(^3\) https://www.sciencedirect.com/science/article/pii/S1552526012025010#bib30

\(^4\) https://jamanetwork.com/journals/jamaneurology/fullarticle/793869

\(^5\) http://www.psychiatrist.com/JCP/article/Pages/2017/v78n08/16m11367.aspx

\(^6\) https://www.ncbi.nlm.nih.gov/pubmed/24962204

\(^7\) https://www.ncbi.nlm.nih.gov/pubmed/27653867
Additional questions associated with satisfaction with the course include:

**How would you rate your overall satisfaction with the location of the program?** [Satisfied With Location]

Very Dissatisfied, Dissatisfied, Okay, Satisfied, Very Satisfied

**How would you rate your overall satisfaction with the time of the program?** [Satisfied with Time]

Very Dissatisfied, Dissatisfied, Okay, Satisfied, Very Satisfied

**How would you rate your overall satisfaction with the leader(s) of the program?** [Satisfied with Leader]

Very Dissatisfied, Dissatisfied, Okay, Satisfied, Very Satisfied

*Why this matters:* Understanding the satisfaction with the program can provide insight into many aspects of its delivery. You should use program level data to understand the logistical side of program planning, including satisfaction with the leaders, the time offered, the location, and other factors you may not have considered. This is part of the continuous quality improvement process.

### Referrals

Wondering whether your marketing and recruitment efforts are paying off? Curious if that new partnership with the local clinic is yielding a steady flow of referrals? Did anyone act on your Facebook ads and social media campaigns?

You can use several options in the database to create your own questions and track the effectiveness of your efforts.

You can phrase your question in your survey in a number of ways. One example is:

**Where did you hear about [program name]?** *(Please put “X” in all boxes that apply, e.g. ☒)* [Referral Source]

- ☐ I was referred by my doctor or other medical provider
- ☐ I heard about it from friends or family
- ☐ This is a benefit offered through my health insurance
  
  If yes, please name health insurance plan: ______________________________________________________
- ☐ I responded to an advertisement or invitation from a local organization
  
  If yes, please name the organization: ____________________________________________________________
- ☐ I heard about it through social media (e.g. Facebook)
  
  If yes, please specify: ____________________________________________________________
- ☐ Other, please specify: _________________________________________________________________
Why this matters: Use this question if you are interested in knowing how participants found out about the program to better inform how you spend your resources on advertising. This could also be an important question to ask to identify which providers are referring their patients to your program. This would be an opportunity to collaborate and partner to enhance and expand referral sources.

Workshop Level

The following optional fields are not marked as such in the workshop data entry user interface.

Funding Source

Many organizations are often pulling from various funding streams or sharing other resources (e.g. personnel, licenses, space) to support any given workshop. To help track the funding source for each workshop, we encourage you to collect this data on the "Program Information Cover Sheet". Please note that the Administration for Community Living (ACL) permits active grantees to count Title III-D funded workshops toward their PPHF grant goals. This option was added in 2016 and revised in August 2018. You can select multiple funding sources in the system by holding down the Ctrl button and clicking on all the funding sources you wish to select.

If you scroll the bar on the right, you’ll see an extensive listing of funding sources.

- ACL CDSME Grant
- Other Federal Funding
- Older Americans Act (Title III-D, Title III-E, etc.)
- Centers for Disease Control and Prevention
- Medicaid / Medicaid Waiver
- Medicare Advantage
- Other Health Care Payer
- Foundation Funding
- Corporate sponsor
- Don’t Know
- Other

Please contact the data manager if you require additional options.

Program Format
For many years, organizations only tracked in-person programs in the National CDSME Database. With many programs now offered in multiple formats, NCOA is interested in monitoring differences in the demographic of participants who elect one format vs another; examining completion rates; and mapping the growth of these alternate program formats. Currently, the optional item on the workshop profile interface allows users to document this format. This question was introduced in 2017 and additional format types were added in August 2018. [Format]

Under Workshop Format, select from the drop-down menu:
- in person (group)
- one-on-one
- online
- hybrid (mix of online + in-person)
- self-directed/at home