





#### **Behavioral Risk Factor Surveillance System**

Alzheimer's Disease and Healthy Aging Program

National Center for Chronic Disease Prevention and Health Promotion

Centers for Disease Control and Prevention

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## **Objective**

The purpose of this document is to provide guidance for BRFSS coordinators and researchers who would like to analyze data collected through the 2015-2018 BRFSS Cognitive Decline Optional Module through the use of consistent analytic methods.

## **Background**

Recognizing the importance of cognitive decline as a public health issue, the CDC Alzheimer's Disease and Healthy Aging Program, in collaboration with national experts, developed and implemented a module to monitor subjective cognitive decline and its associated effect or burden in the population.

The Cognitive Decline Module was offered for the first time in 2011 as the Cognitive Impairment Module after extensive cognitive testing. From 2011 through 2013, a total of 47 states and territories added the module (as an official optional module in 2011 and as state-added questions in 2012 and 2013). CDC then consulted with data users and convened a panel to revise the module based on feedback. The revised module underwent two rounds of cognitive testing before it was finalized and approved by BRFSS coordinators to be included as an official Optional Module in the 2015 BRFSS.

Healthy People 2020 has multiple objectives targeting cognitive function that could be measured through ongoing surveillance. See Appendix A for the following:

**Dementias including Alzheimer's disease:** Objective DIA-1 Increase the proportion of persons with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis

**Dementias including Alzheimer's disease:** Objective DIA-2 Reduce the proportion of preventable hospitalizations in adults aged 65 years and older with diagnosed Alzheimer's disease and other dementias

**Older Adults:** Objective OA-5 Reduce the proportion of older adults who have moderate to severe functional limitations

**Older Adults:** Objective OA-6 Increase the proportion of older adults with reduced physical or cognitive function who engage in light, moderate, or vigorous leisure-time physical activities

The CDC Alzheimer's Disease and Healthy Aging Program provides selected analyses of these data on their Alzheimer's Disease and Healthy Aging website.



## **Cognitive Decline Module History**

In 2011, the BRFSS questionnaire included a set of 10 questions collectively referred to as the Cognitive Impairment Optional Module (now Cognitive Decline). Twenty-one states implemented the optional module in 2011, including 14 states as state added questions. The results were published in the MMWR article "Self-reported Increased Confusion or Memory Loss and Associated Functional Difficulties Among Adults Aged ≥60 years—21 states, 2011." In 2012, the Cognitive Impairment Optional Module was implemented as state-added questions and data are available only by request to participating states.

Modified for 2015, The 6-question Cognitive Decline Module examines how cognitive decline affects the lives of respondents aged 45 years and older, including people with difficulties performing activities or caring for themselves. Estimating the prevalence of cognitive decline and these associated limitations may allow states to plan for people who might develop dementia in the future. These questions can also help support states in their efforts to assess progress toward Healthy People 2020 objectives related to cognitive decline (Appendix A).

This set of questions is currently an optional BRFSS module, and states can choose to administer the survey questions as part of their BRFSS administration

## **Analytic Code**

Questions on the module address "confusion or memory loss" during the past 12 months "that is happening more often or is getting worse." Prior to 2015, this measure was referred to as "increased confusion or memory loss (ICML)," and is now called "subjective cognitive decline (SCD)." As is true of all BRFSS questions, this confusion or memory loss is self-reported. Additional questions for adults with SCD measure the impact of SCD on daily activities, need for assistance, the frequency that assistance or care is received from a family member or friend, and whether the SCD was discussed with a health care professional.

The sections below describe each item and include sample Stata and SAS code to prepare the variables for analyzing the data. The variable names used to create recoded variables are the CDC assigned variable names for each question. For most questions, "don't know/not sure" and "refused" responses are set to missing; however, there may be circumstances when "missing" responses may be appropriate to include in the denominator. The full text of the 2018 Cognitive Decline Module appears in Appendix B. Older versions of the module can be found on the BRFSS website.

### **Subjective Cognitive Decline Status**

The SCD Module is asked of adults aged 45 years and older and begins with introductory text, read by the interviewer, that describes the type of cognitive changes the module is addressing to distinguish it from forgetfulness: The SCD Module begins with the following screening question, which differs slightly from the original one used on the 2011 BRFSS core, to identify cognitive decline status:

Q1. During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?

1—Yes

2—No [GO TO NEXT MODULE]

7—Don't know/Not sure [GO TO Q2]

9—Refused [GO TO NEXT MODULE]

**VARIABLE NAME: CIMEMLOS** 

The analytic code creates variables for participants experiencing cognitive decline. The code is used to classify respondents who say "yes" to the screening question as individuals who may be experiencing SCD and respondents who say "no" as not experiencing SCD. All other respondents are coded as missing. Note that respondents who say, "don't know/not sure" in response to this question are asked subsequent module questions and therefore analysts may choose to code "don't know" responses as experiencing SCD; this decision will depend on the purpose of the analysis.

#### Subjective Cognitive Decline Status

Software	Analytic Code
STATA	cimemlos (7/9=.), g(cimemlos_rc) recode cimemlos (1=1) (2=0) (7=.) (9=.), g(scd)
SAS	cimemlos_rc = cimemlos; if cimemlos in (7,9) then cimemlos_rc = .; if cimemlos=1 then scd = 1; if cimemlos = 2 then scd = 0; if cimemlos in (7,9) then scd = .;

The remaining questions are asked only of respondents who were classified as having SCD or who did not know if they experienced SCD in the screening question (i.e., cimemlos=1 or cimemlos=7).



## Interference with Day-to-Day Activities

The second question in the module deals with loss of ability to perform daily household activities or chores. Participants experiencing SCD are asked how often confusion or memory loss interferes with day-to-day activities. Analysts could use this information to identify people with loss of daily function due to cognitive decline. Responses "always," "usually," or "sometimes" may be combined to identify respondents who experience the loss of daily function due to cognitive decline and responses "rarely" or "never" combined to identify respondents who have not experienced the loss.

Q2. During the past 12 months, as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills? Would you say it is...

1—Always

2—Usually 7—Don't know/Not sure

3—Sometimes 9—Refused

4—Rarely VARIABLE NAME: CDHOUSE

5—Never

#### Interference with Day-to-Day Activities

Software	Analytic Code
STATA	recode cdhouse (7/9=.), g(cdhouse_rc)
	recode cdhouse (1/3=1) (4/5=0) (7/9=.), g(scd_hhlimit)
SAS	cdhouse_rc = cdhouse; If cdhouse in (7,9) then cdhouse_rc = .;
	if 1<=cdhouse<=3 then scd_hhlimit=1; *Loss of daily function due to cognitive decline;
	if 4<=cdhouse<=5 then scd_hhlimit=2;
	if 7<=cdhouse<=9 then scd_hhlimit=.;



#### **Need for Assistance**

Participants who said they always, usually, or sometimes give up household chores are asked how often they need assistance with said day-to-day activities due to memory loss or confusion. Analysts can use this information to identify people experiencing cognitive decline who often need assistance with day-to-day activities.

Q3. As a result of confusion or memory loss, how often do you need assistance with these day-to-day activities? Would you say it is...

1—Always 9—Refused

2—Usually VARIABLE NAME: CDASSIST

3—Sometimes

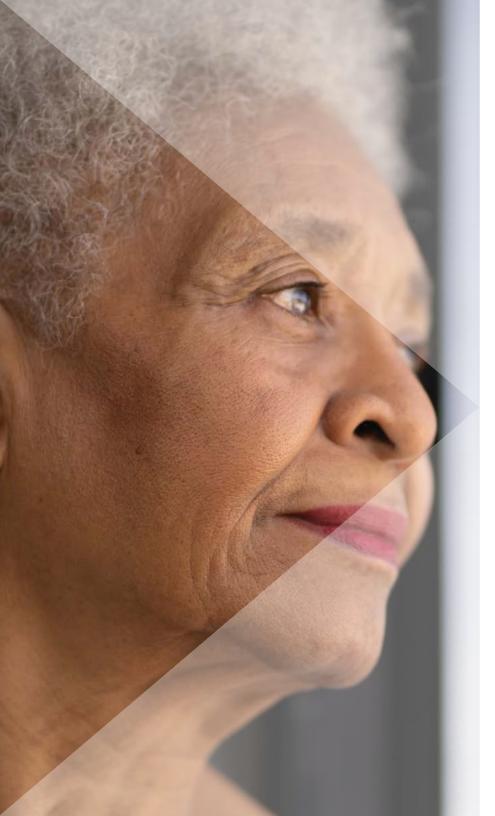
4—Rarely

5—Never

7—Don't know/Not sure

#### **Need for Assistance**

Software	Analytic Code
STATA	recode cdassist (7/9=.), g(cdassist_rc) recode cdassist (1/3=1) (4/5=0) (7/9=.), g(scd_needhelp)
SAS	cdassist_rc = cdassist; if cdassist in (7,9) then cdassist_rc = .;
	if 1<= cdassist<=3 then scd_needhelp=1; *Often need assistance with day-to-day activities;
	if 4<= cdassist<=5 then scd_needhelp=2;
	if 7<= cdassist<=9 then scd_needhelp=.;



## **Ability to Access Assistance**

Participants are asked how often they are able to obtain help to complete day-to-day activities. Analysts can use this information to identify if the needs of those experiencing cognitive decline are being met. Respondents who say "always", "usually", or "sometimes" are classified as getting the help they need when they need it.

Respondents who say "rarely" or "never" are classified as not getting the help they need.

Q4. When you need help with these day-to-day activities, how often are you able to get the help that you need? Would you say it is...

1—Always

2—Usually 7—Don't know/Not sure

3—Sometimes 9—Refused

4—Rarely VARIABLE NAME: CDHELP

5—Never

#### Ability to Access Assistance

Software	Analytic Code
STATA	recode cdhelp (7/9=.), g(cdhelp_rc) recode cdhelp (1/3=1) (4/5=0) (7/9=.), g(scd_needhelp)



#### Interference with Social Activities

Participants are asked how often confusion or memory loss interferes with social activities. Analysts could use this information to identify people whose confusion or memory loss interferes with social activities.

Q5. During the past 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities outside the home? Would you say it is...

1—Always 7—Don't know/Not sure

2—Usually 9—Refused

3—Sometimes VARIABLE NAME: CDSOCIAL

4—Rarely 5—Never

#### Interference with Social Activities

Software	Analytic Code
STATA	recode cdsocial (7/9=.), g(cdsocial_rc) recode cdsocial (1/3=1) (4/5=0) (7/9=.), g(scd_sociallimit)
SAS	cdsocial_rc = cdsocial; If cdsocial in (7,9) then cdsocial_rc = .;
	if 1<=cdsocial<=3 then scd_sociallimit=1; *Confusion or memory loss interferes with social activities; if 4<=cdsocial<=5 then scd_sociallimit=2;
	if 7<=cdsocial<=9 then scd_sociallimit=.;



### **Functional Difficulties Due to Cognitive Decline**

Functional difficulty related to SCD is measured using two questions about household and social limitations. The code below creates a variable to identify respondents who experience at least one of these types of limitations as a result of their SCD.

Respondents missing information for both items (cdhouse or cdsocial) are classified as missing in the code below.

Q2. During the past 12 months, as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills?

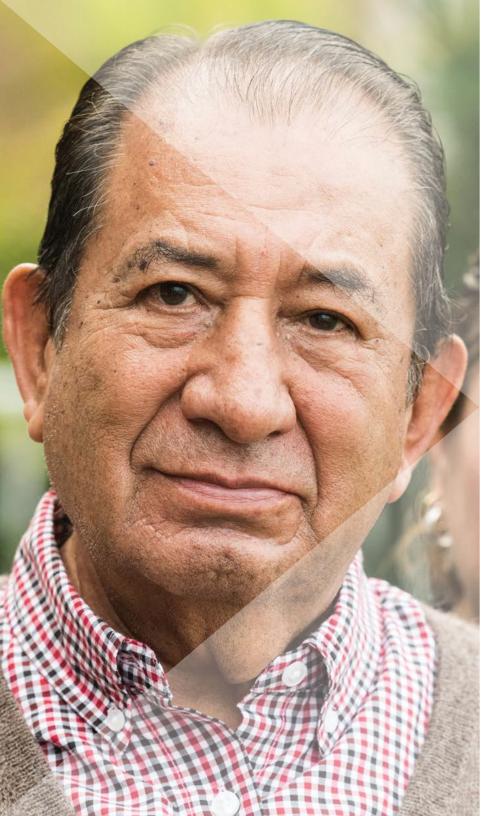
**VARIABLE NAME: CDHOUSE** 

Q5. During the past 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities outside the home?

**VARIABLE NAME: CDSOCIAL** 

#### Functional Difficulties Due to Cognitive Decline

Software	Analytic Code
STATA	g scd_functdiff=.  replace scd_functdiff=1 if inrange(cdhouse,1,3)   inrange(cdsocial,1,3)  replace scd_functdiff =0 if inrange(cdhouse,4,5) & inrange(cdsocial,4,5)
SAS	If cdhouse in (1,2,3) or cdsocial in (1,2,3) then scd_functdiff=1; *At least one type of limitation (household or social); if cdhouse in (4,5) and cdsocial in (4,5) then scd_functdiff=2;



## Discussion of Cognitive Decline with Health Care Professional

Participants are asked whether they have discussed their confusion or memory loss with a health care professional. Analysts could use this information to estimate the number of people who have discussed cognitive decline with a health care professional.

Q6. Have you or anyone else discussed your confusion or memory loss with a health care professional?

- 1—Yes
- 2—No
- 3—Don't know/Not sure
- 4—Refused

#### Subjective Cognitive Decline Status

Software	Analytic Code
STATA	recode cddiscus (1=1) (2=0) (7/9=.), g(scd_discuss)
SAS	scd_discuss=cddiscus; if cddiscus in (7,9) then scd_discuss=.;



#### References

- Adams ML, Deokar AJ, Anderson LA, Edwards VJ. Self-reported increased confusion or memory loss and associated functional difficulties among adults aged ≥60 years—21 states, 2011. Morb Mortal Wkly Rep MMWR. 2013;62(18);347–350.
- 2. Taylor CA, Bouldin ED, McGuire LC. <u>Subjective cognitive decline among adults aged</u> ≥45 years—United States, 2015–2016. *Morb Mortal Wkly Rep MMWR*. 2018;67:753–757.
- 3. US Department of Health and Human Services (US DHHS). Office of Disease Prevention and Health Promotion. Healthy People 2020 Dementias Including Alzheimer's Disease; Older Adults website. <a href="https://www.healthypeople.gov/2020/topics-objectives">https://www.healthypeople.gov/2020/topics-objectives</a>. Accessed December 9, 2019.

## Appendix A: Healthy People 2020 Objectives Related to Cognitive Decline

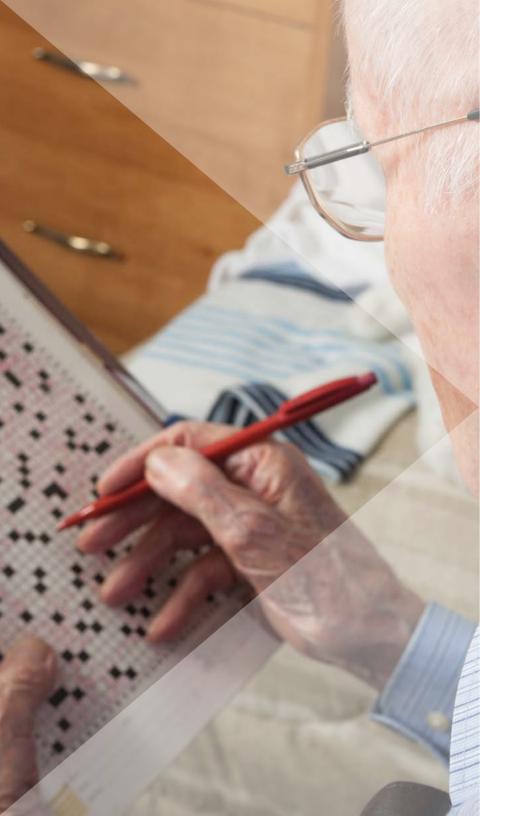
- **DIA-1** Increase the proportion of persons with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis
- **DIA-2** Reduce the proportion of preventable hospitalizations in adults aged 65 years and older with diagnosed Alzheimer's disease and other dementias
- **OA-5** Reduce the proportion of older adults who have moderate to severe functional limitations
- **OA-6** Increase the proportion of older adults with reduced physical or cognitive function who engage in light, moderate, or vigorous leisure-time physical activities

## Appendix B: BRFSS 2018 Cognitive Decline Module

The next few questions ask about difficulties in thinking or remembering that can make a big difference in everyday activities. This does not refer to occasionally forgetting your keys or the name of someone you recently met, which is normal. This refers to confusion or memory loss that is happening more often or getting worse, such as forgetting how to do things you've always done or forgetting things that you would normally know. We want to know how these difficulties impact you.

- 1. During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?
  - 01—Yes
  - 02—No—[Go to next module]
  - 07—Don't know/Not sure
  - 09—Refused—[Go to next module]
- 2. During the past 12 months, as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills? Would you say it is...
  - 01—Always
  - 02—Usually
  - 03—Sometimes
  - 04—Rarely—[Go to Question 5]
  - 05—Never—[Go to Question 5]
  - 07—Don't know/ Not sure—[Go to Question 5]
  - 09—Refused—[Go to Question 5]
- 3. As a result of confusion or memory loss, how often do you need assistance with these day-to-day activities? Would you say it is...
  - 01—Always
  - 02—Usually
  - 03—Sometimes
  - 04—Rarely
  - 05—Never
  - 07—Don't know/ Not sure
  - 09—Refused

- 4. When you need help with these day-to-day activities, how often are you able to get the help that you need? Would you say it is...
  - 01—Always
  - 02—Usually
  - 03—Sometimes
  - 04—Rarely
  - 05—Never
  - 07—Don't know/ Not sure
  - 09—Refused
- 5. During the past 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities outside the home? Would you say it is...
  - 01—Always
  - 02—Usually
  - 03—Sometimes
  - 04—Rarely
  - 05—Never
  - 07—Don't know/ Not sure
  - 08—Refused
- 6. Have you or anyone else discussed your confusion or memory loss with a health care professional?
  - 01—Always
  - 02—Usually
  - 03—Sometimes
  - 04—Rarely
  - 05—Never
  - 07—Don't know/ Not sure
  - 09—Refused



#### **Selected Scientific Publications**

Adams, M. L., Grandpre, J., Katz, D. L., & Shenson, D. (2019). The impact of key modifiable risk factors on leading chronic conditions. Preventive Medicine, 120, 113–118. doi: 10.1016/j.ypmed.2019.01.006

Brown, M. J., & Patterson, R. (2020). Subjective Cognitive Decline Among Sexual and Gender Minorities: Results from a U.S. Population-Based Sample. Journal of Alzheimers Disease, 73(2), 477–487. doi: 10.3233/jad-190869

Burns, S. P., Mueller, M., Magwood, G., White, B. M., Lackland, D., & Ellis, C. (2019). Racial and ethnic differences in post-stroke subjective cognitive decline exist. Disability and Health Journal, 12(1), 87–92. doi: 10.1016/j.dhjo.2018.08.005

Marrone, N., Ingram, M., Bischoff, K., Burgen, E., Carvajal, S. C., & Bell, M. L. (2019). Self-reported hearing difficulty and its association with general, cognitive, and psychosocial health in the state of Arizona, 2015. BMC Public Health, 19(1). doi: 10.1186/s12889-019-7175-5

Peterson, R. L., Carvajal, S. C., Mcguire, L. C., Fain, M. J., & Bell, M. L. (2019). State inequality, socioeconomic position and subjective cognitive decline in the United States. SSM - Population Health, 7, 100357. doi: 10.1016/j. ssmph.2019.100357

Taylor, C. A., Bouldin, E. D., Greenlund, K. J., & Mcguire, L. C. (2020). Comorbid Chronic Conditions Among Older Adults with Subjective Cognitive Decline, United States, 2015–2017. Innovation in Aging, 4(1). doi: 10.1093/geroni/igz045

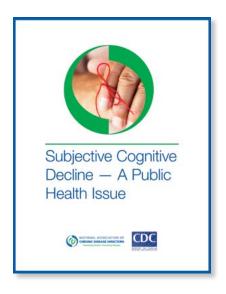
Taylor, C. A., Bouldin, E. D., & Mcguire, L. C. (2019). Chronic Diseases In Middle-Aged Adults With Subjective Cognitive Decline: United States, 2015-2017. Innovation in Aging, 3(Supplement\_1). doi: 10.1093/geroni/igz038.3007

## **Data For Action: Selected Examples**



## Infographics

The 2015-2018 Subjective Cognitive Decline (SCD) infographic utilizes key BRFSS data from the Cognitive Decline module. The infographics are available <a href="https://www.cdc.gov/aging/data/index.html">https://www.cdc.gov/aging/data/index.html</a> nationally, by state, and for several demographic groups, in both English and Spanish.



## State of Aging and Health in America: Data Brief Series

The Subjective Cognitive Decline (SCD) Data Brief utilizes BRFSS data from the Cognitive Decline module. The SCD brief includes the most recent data available on SCD and aging related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population.

Full brief: https://www.cdc.gov/aging/publications/briefs.htm

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