





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 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 2030 has multiple objectives targeting cognitive function that could be measured through ongoing surveillance.¹ See Appendix A for the following:

Health Conditions — **Dementias: Objective DIA-01** — Increase the proportion of older adults with dementia, or their caregivers, who know they have it.

Health Conditions — Dementias: Objective DIA-02 — Reduce the proportion of preventable hospitalizations in older adults with dementia.

Health Conditions — **Dementias: Objective DIA-03** — Increase the proportion of adults with subjective cognitive decline who have discussed their symptoms with a provider.

Health Conditions — Older Adults: Objective OA-01 — Increase the proportion of older adults with physical or cognitive health problems who get physical activity.

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



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 2030 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 = .; *DK/Ref;
	if cimemlos=1 then scd = 1; *Yes; if cimemlos =2 then scd =0; *No; if cimemlos in (7,9) then scd =:; *DK/Ref;

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 7—Don't know/Not sure

2—Usually 9—Refused

3—Sometimes VARIABLE NAME: CDHOUSE

4—Rarely

5—Never

Interference with Day-to-Day Activities

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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 = .; *DK/ref;
	if cdhouse in (1:3) then scd_hhlimit=1; *Loss of daily function due to cognitive decline; if cdhouse in (4,5) then scd_hhlimit=0; *No/minimal loss of daily function due to cognitive decline; if cdhouse in (7,9) then scd_hhlimit=; *DK/ref;



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 7—Don't know/Not sure

2—Usually 9—Refused

3—Sometimes VARIABLE NAME: CDASSIST

4—Rarely

5—Never

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 = .; *DK/ref;
	if cdassist in (1:3) then scd_needhelp=1; *Often need assistance with day-to-day activities; if cdassist in (4,5) then scd_needhelp=0; *Never/rarely needs assistance with day-to-day activities; if cdassist in (7,9) then scd_needhelp=; *DK/ref;



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 7—Don't know/Not sure

2—Usually 9—Refused

3—Sometimes VARIABLE NAME: CDHELP

4—Rarely

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_gethelp)
SAS	cdhelp_rc=cdhelp; if cdhelp in (7,9) then cdhelp_rc = .; *DK/ref;
	if cdhelp in (1:3) then scd_gethelp = 1; *Often gets needed assisance; if cdhelp in (4,5) then scd_gethelp = 0;
	*Rarely/never gets needed assistance; if cdhelp in (7,9) then scd_gethelp = .; *DK/ref;



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 = .; *DK/ref; if cdsocial in (1:3) then scd_sociallimit=1; *Confusion/memory loss interferes with social activities; if cdsocial in (4,5) then scd_sociallimit=0; *Confusion/memory loss does not interferes with social activities; if cdsocial in (7,9) then scd_sociallimit=.; *DK/ref;



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?

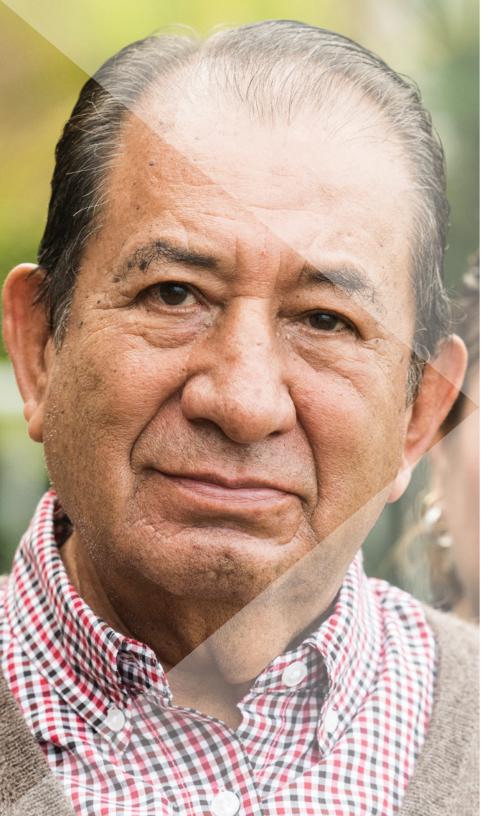
VARIABLE NAME: CDHOUSE

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=0;
	*No limitation (household or social);



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

VARIABLE NAME: CDDISCUS

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 = 2 then scd_discuss=0; *No; if cddiscus in (7,9) then scd_discuss=.; *DK/ref;



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.
- 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. U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. Healthy People 2030: Older Adults. Washington, DC. Available at: https://health.gov/healthypeople/objectives-and-data/browse-objectives/older-adults. Accessed January 5, 2021.

Appendix A: Healthy People 2030 Objectives Related to Cognitive Decline

Health Conditions — **Dementias: Objective DIA-01** — Increase the proportion of older adults with dementia, or their caregivers, who know they have it.

Health Conditions — **Dementias: Objective DIA-02** — Reduce the proportion of preventable hospitalizations in older adults with dementia.

Health Conditions — Dementias: Objective DIA-03 — Increase the proportion of adults with subjective cognitive decline who have discussed their symptoms with a provider.

Health Conditions — **Older Adults: Objective OA-01** — Increase the proportion of older adults with physical or cognitive health problems who get physical activity.

Appendix B: BRFSS 2015-Present 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
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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
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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

09—Refused

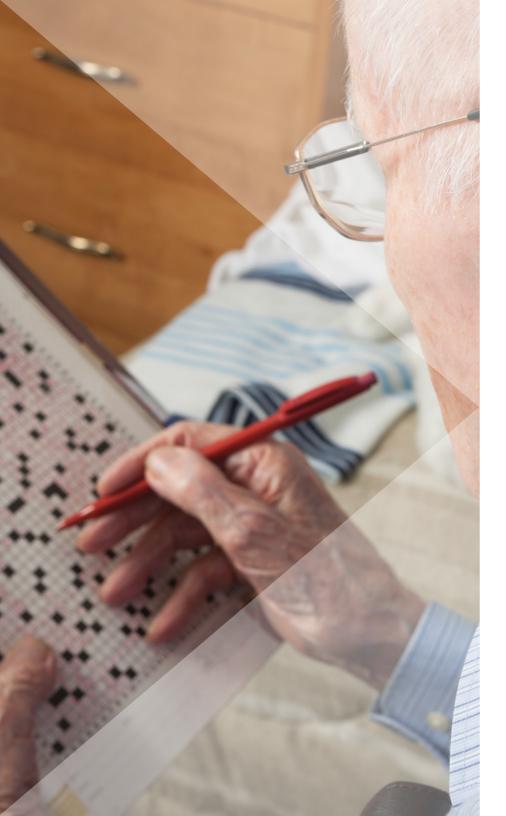
6. Have you or anyone else discussed your confusion or memory loss with a health care professional?

01—Yes

02—No

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

Bouldin ED, Taylor CA, Knapp KA, Miyawaki CE, Mercado NR, Wooten KG, McGuire LC. Unmet needs for assistance related to subjective cognitive decline among community-dwelling middle-aged and older adults in the US: prevalence and impact on health-related quality of life. Int Psychogeriatr. 2020;1-14. doi:10.1017/S1041610220001635

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

Omura JD, Brown DR, McGuire LC, Taylor CA, Fulton JE, Carlson SA. Cross-sectional association between physical activity level and subjective cognitive decline among US adults aged ≥45 years, 2015. Prev Med. 2020 Oct 6;141:106279. doi: 10.1016/j. ypmed.2020.106279

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

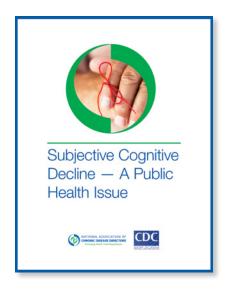
Taylor, C. A., Bouldin, E. D., & Mcguire, L. C. (2019). Chronic Diseases In Middle-Aged Adults With Subjective Cognitive Decline: United States, 2015-2017. Innovation in Aging, 3(Supplement_1). doi: 10.1093/geroni/igz038.3007

Data For Action: Selected Examples



Infographics

The Subjective Cognitive Decline (SCD) infographic series utilizes key BRFSS data from the Cognitive Decline module. The infographics are available https://www.cdc.gov/aging/data/index.html 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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