



New and Revised Measures in the Medicare Health Outcomes Survey (HOS) Instrument Starting in 2013

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The Surveillance, Epidemiology and End Results (SEER)-Medicare Health Outcomes Survey (SEER-MHOS) is a data resource for cancer health outcomes research. It is based on a linkage between the National Cancer Institute's (NCI) [Surveillance, Epidemiology and End Results \(SEER\)](#) cancer registry data and the Centers for Medicare & Medicaid Services' (CMS) [Health Outcomes Survey \(HOS\)](#). The SEER registry contains data on patient cancer details, treatment, and sociodemographic factors, while the HOS reports on topics such as: health-related quality of life, activities of daily living, and effectiveness of care. SEER-MHOS links these two data sources, Medicare enrollment, and Part D prescription drug claims. Together, this creates a data resource focused on measuring cancer patient and survivor health-related quality of life (HRQOL).

The Medicare HOS survey has been updated several times since it began in 1998. In the Spring of 2006, CMS replaced the original survey with the Medicare HOS 2.0. The new version replaced the HRQOL measure with a short form (SF-36 to VR-12), removed redundant or less useful items (Urinary incontinence, stroke complications), added two HEDIS® measures (osteoporosis testing and fall risk management), and height and weight questions for calculation of Body Mass Index.

In 2011, the National Committee for Quality Assurance (NCQA), under the direction of CMS, identified new domains and measures to add value to the survey. This led to multiple survey revisions adding many new topics and measures that can be used by SEER-MHOS investigators. This report provides background and scoring for all Health Outcomes Survey (HOS) measures added or modified since 2013 (HOS versions 2.5 and 3.0).

Copies of the HOS survey instruments are available upon request from NCQA's [website](#). Visit [HOS online](#) for more information about the HOS, and visit the [SEER-MHOS website](#) or email SEER-MHOS@hsag.com for more information about the linked data resource.

Items in the Current HOS Instrument Added during the 2013 HOS Version 2.5 Update^a

Instrumental Activities of Daily Living (IADLs) HOS 2.5, 3.0 (2013–Current)

Background

Instrumental Activities of Daily Living (IADLs) assess independent living skills that are more complex than Activities of Daily Living (ADLs).^{1,2} IADLs recognize early changes in functioning, and can indicate the need for intervention or further medical work-up.² Occupational therapists commonly assess IADLs in the rehabilitation setting to determine the level of an individual's need for assistance and cognitive function.³ Although not necessary for functional living, the ability to perform IADLs can significantly improve the quality of life. Regular assessment of functional status is recommended for improving the effectiveness of care, especially for older adults prior to hospital discharge and those living with dementia.⁴

Scoring

The HOS includes only three of the eight IADL questions developed by Lawton and, therefore, cannot be scored on the Lawton 8-Point Scale.¹ The three HOS IADL measures can be scored as single items. It is recommended to treat the response "I don't do this activity" as non-informative because the HOS IADL items do not contain a follow up question to ascertain if this response was due to a health or physical problem.⁴

Question(s)

Q11a-c: Because of a health or physical problem, do you have any difficulty doing the following activities? a) Preparing meals b) Managing money c) Taking medications as prescribed

Response categories

- No, I do not have difficulty
- Yes, I have difficulty
- I don't do this activity

Vision and Hearing (Revised) HOS 2.5, 3.0 (2013–Current)

Background

The vision and hearing questions were reworded, and the direction of the responses was reversed in HOS 2.5. The vision and hearing questions are required under Section 4302 of the Affordable Care Act (ACA). Section 4302 requires the Secretary of DHHS to establish data collection standards for race, ethnicity, sex, primary language, and disability status.⁵ These questions have been used in the U.S. Census American Community Survey (ACS) since 2008.⁶ The ACS Subcommittee on Disability Measurement found that surveys could identify certain aspects of disability and estimate a population who would be likely to experience restrictions in participation due to physical, social, and other environmental barriers.⁷

Scoring

The two HOS vision and hearing questions can be scored as single items. Use caution if linking the previous version of the vision and hearing questions (HOS 1.0, 2.0; 1998–2012), where "no" responses indicated impairment, to the revised questions (HOS 2.5, 3.0; 2013–present) where "yes" responses indicate impairments.

^a Items added in the 2013 HOS 2.5, but removed from the survey in 2014 prior to the HOS 3.0 include: *Do you have serious difficulty walking or climbing stairs?; Do you have difficulty dressing or bathing?; Do you currently provide care for someone else in your home?; During the past week, how many days did you provide at least some care?; Do you have difficulty getting to places you need to go (either by driving or by getting a ride)?*

Question(s)

Q15. Are you blind or do you have serious difficulty seeing, even when wearing glasses?

Response categories

- Yes, No

Question(s)

Q16. Are you deaf or do you have serious difficulty hearing, even with a hearing aid?

Response categories

- Yes, No

Concentrating, Doing Errands, and Memory Problems HOS 2.5, 3.0 (2013–Current)

Background

These additional disability questions capture a domain previously missing from the HOS. The difficulty concentrating and difficulty doing errands questions are required under Section 4302 of the ACA⁵ and are used in the ACS.⁶ The memory problems question is also used in the National Health and Aging Trends Study (NHATS).⁸

Scoring

The concentrating, doing errands, and memory problem questions can be scored as single items.

Question(s)

Q17. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering or making decisions?

Response categories

- Yes, No

Question(s)

Q18. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

Response categories

- Yes, No

Question(s)

Q19. In the past month, how often did memory problems interfere with your daily activities?

Response categories

• Every day (7 days a week)	• Rarely (once a week or less)
• Most days (5-6 days a week)	• Never
• Some days (2-4 days a week)	

New Chronic Condition Questions (Depression and Self-reported Cancer during Treatment) HOS 2.5, 3.0 (2013–Current)

Background

The chronic condition depression item was added to the CMS Health Plan Management System (HPMS) aggregate score analysis of beneficiary chronic conditions.⁹ The other cancer (other than skin cancer) option was added to provide a catch-all category for those beneficiaries who were under treatment for a cancer not listed in Q35a-d. These self-reported responses may not correspond to linked SEER or other clinician diagnoses and should be used with caution. Also of note, HOS respondents who self-report cancer treatment but are not in the SEER registry are included in the linked SEER-MHOS data with only MHOS information.

Scoring

The chronic condition depression and cancer under treatment questions are scored as single items. Chronic condition depression can be aggregated with the other 14 chronic condition HOS questions to report a comorbidity count (none, one, two, three, or four or more conditions).¹⁰

Question(s)

Q33. Has a doctor ever told you that you had: Depression?

Q35e. Are you currently under treatment for: Other cancer (Other than skin cancer)?

Response categories

- Yes, No

Patient-Reported Outcomes Measurement Information System (PROMIS) Pain Items HOS 2.5, 3.0 (2013–Current)

Background

PROMIS is a set of patient-reported outcome (PRO) measures that evaluate physical, mental, and social health in adults and children. It can be used with the general population and with individuals living with chronic conditions.¹¹ Pain interference and pain intensity questions used in the HOS are taken from the PROMIS Profile-29 v1.0, modified to fit the needs of the HOS instrument.^{11,12} The HOS 2.5 was first implemented in the *Cohort 16 Baseline* (and *Cohort 14 Follow Up*) survey fielded in 2013.

Scoring

PROMIS Pain Interference (Q36, Q37) should only be reported as a T Score. Scoring information, SAS programming code, and look-up tables for use with the HOS are available on the [SEER-MHOS website](#). PROMIS Pain Intensity (Q38) is a single item using a modified non-standard scale starting at 1 (vs. 0) and is not comparable to other PROMIS pain intensity scores.

Question(s)

Q36. In the past 7 days, how much did pain interfere with your day to day activities?

Response categories

- Not at all
- Quite a bit
- A little bit
- Very much
- Somewhat

Question(s)

Q37. In the past 7 days, how often did pain keep you from socializing with others?

Response categories

- Never
- Often
- Rarely
- Always
- Sometimes

Question(s)

Q38. In the past 7 days, how would you rate your pain on average?

Response categories

- Scale ranging from 1=No pain to 10=Worst imaginable pain

Depression Patient Health Questionnaire-2 (PHQ-2) Questions (Revised) HOS 2.5, 3.0 (2013-Current)

Background

Beginning with the 2013 HOS 2.5, two depression screening questions from the PHQ-2¹³ replaced the depression screening measure in previous versions of the HOS (Questions 36–39 on the 2012 HOS 2.0 Instrument and the Glossary description of the depression screen at <https://www.hosonline.org/en/glossary>).

Scoring

Each depression question is assigned points depending on the response given, from 1 ("Not at all") to 4 ("Nearly every day"). The survey coded responses for Questions 39a-b are transformed to 0–3 and the points are summed. A positive depression screen threshold is a total score of ≥ 3 points.¹⁴

Due to the change in the depression screening tools and scoring, individual total scores cannot be averaged or pooled comparatively across HOS versions. Prior to HOS 2.5, the depression screening questions described levels of depression that encompassed feeling sad or blue for two weeks or more in the past year, depressed for much of the past year, depressed for two years or more in life, or depressed for some or more of the time in the past week.¹⁵ The depression screen threshold may not be consistent across survey versions and should be evaluated carefully.

Question(s)

Q39a-b. Over the past 2 weeks, how often have you been bothered by any of the following problems?

- a) Little interest or pleasure in doing things
- b) Feeling down, depressed, or hopeless

Response categories:

- Not at all
- Several days
- More than half the days
- Nearly every day

Ethnicity and Race Questions (Revised) HOS 2.5, 3.0 (2013–Current)

Background

The expanded self-reported ethnicity and race questions are required under Section 4302 of the ACA.⁵ Section 4302 requires the Secretary of DHHS to establish data collection standards for race, ethnicity, sex, primary language, and disability status. When available, self-reported ethnicity and race at baseline are also used in the initial case-mix adjustment models of the physical component summary (PCS) and mental component summary (MCS) scores, and death outcome. The expanded questions meet the Office of Management and Budget (OMB) standards for determining an individual's ethnicity and race, encourage additional granularity when supported by sample size, and, when available, are preferred over the CMS administrative race variable as a means of classifying HOS respondents.⁵ Evidence from several studies suggests the differences in health among Medicare eligible beneficiaries by racial groups.^{16,17,18,19,20,21}

Scoring

Responses may include one or more Hispanic ethnicity and race categories.

Question(s)

Q58. Are you Hispanic, Latino/a or Spanish origin? (One or more categories may be selected)

Response categories

- No, not of Hispanic, Latino/a or Spanish origin
- Yes, Mexican, Mexican American, Chicano/a
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino/a or Spanish origin

Question(s)

Q59. What is your race? (One or more categories may be selected)

Response categories

- White
- Black or African American
- American Indian or Alaska Native
- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian
- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander

Living Arrangement Questions HOS 2.5, 3.0 (2013–Current)

Background

The living arrangement questions were derived from living arrangement items used in other large population-based studies of older adults.

Scoring

Living arrangement questions are scored as single items, not as a scale.

Question(s)

Q63. Do you live alone or with others? (One or more categories may be selected)

Response categories:

- Alone
- With spouse/significant other
- With children/other relatives
- With non-relatives
- With paid caregiver

Question(s)

Q64. Where do you live?

Response categories:

- House, apartment, condominium or mobile home
- Assisted living or board and care home
- Nursing home
- Other

Items in the Current Instrument Added during the 2015 HOS Version 3.0 Update^b

Impact of Urinary Incontinence (UI) Question (Revised) HOS 2.5, 3.0 (2013–Current)

Background

Urinary incontinence (UI) may cause a wide range of morbidities, including cellulitis, pressure ulcers, urinary tract infections, falls with fractures, sleep deprivation, social withdrawal, depression, and sexual dysfunction.^{22, 23} Beneficiaries with UI are not often being asked about their UI by a health care professional.²⁴ Consequently, UI remains significantly underreported and underdiagnosed.²⁵

The Healthcare Effectiveness Data and Information Set (HEDIS®)^b HOS question “how much of a problem, if any, was urine leakage” was updated to: “how much did leaking of urine change the daily activities or interfere with sleep.”

Scoring

The HEDIS results are process measures intended to inform Medicare Advantage Organizations (MAOs) of their performance, therefore, scoring for this quality indicator is aggregated to the health care plan: the percentage of beneficiaries 65 years of age and older who reported having urine leakage in the past six months and who reported that urine leakage made them change their daily activities or interfered with their sleep a lot. A lower rate indicates better MAO performance for this indicator.²⁶ There were no changes for use at the individual patient level.

Question(s)

Q43. During the past six months, how much did leaking of urine make you change your daily activities or interfere with your sleep?

Response categories

- A lot
- Somewhat
- Not at all

Sleep Duration and Quality Questions HOS 2.5, 3.0 (2013–Current)

Background

The sleep duration and quality items are derived from the Pittsburgh Sleep Quality Index (PSQI).²⁷ The questions focus on “habitual” (i.e., past month) sleep duration and quality, rather than past week measures, to capture more chronic sleep disturbances. Over half of older adults suffer from symptoms of insomnia, a common problem related to aging.²⁸ Sleep disorders in the elderly can be caused by a number of factors, including medication, diseases, poor sleeping habits, and age-related changes in circadian sleep/wake regulation. There is substantial evidence linking insufficient sleep duration and poor sleep quality to mental and physical health morbidity and mortality.²⁹ Various epidemiologic findings associate sleep duration outside of the recommended number of hours (7–8 hours for adults aged 65 or older) with obesity, diabetes, impaired glucose tolerance, hypertension, and mortality. People who report fair or poor health are less likely to overestimate sleep hours and report shorter sleep hours on average than those with better self-rated health.³⁰

^b HEDIS® is a registered trademark of the National Committee for Quality Assurance (NCQA).

Scoring

The PSQI and HOS sleep quality response options are: "Very good," "Fairly good," "Fairly bad," and "Very bad."³¹ The HOS sleep duration question is categorized into four responses that do not match the PSQI scoring for open-ended sleep duration responses. However, research demonstrates that "7-8 hours" is recommended for respondents 65 years and older.^{32,33,34}

Question(s)

Q53. During the past month, on average, how many hours of actual sleep did you get at night?
(This may be different from the number of hours you spent in bed.)

Response categories

- Less than 5 hours
- 5-6 hours
- 7-8 hours
- 9 or more hours

Question(s)

Q54. During the past month, how would you rate your overall sleep quality?

Response categories

- Very good
- Fairly good
- Fairly bad
- Very bad

Primary Language Question (Revised) HOS 3.0 (2015–Current)

Background

The question which asked how well you speak English was revised to ask what language you mainly speak at home. A character field was added to allow the beneficiary to write in a language other than one of the choices specified. The primary language question is required under Section 4302 of the ACA.⁵ Section 4302 requires the Secretary of DHHS to establish data collection standards for race, ethnicity, sex, primary language, and disability status. The question is based on a similar primary language question used on the ACS.³⁵

Scoring

The language question is scored as a single item. Responses to "some other language" are recorded as specified by the beneficiary.

Question(s)

Q60. What language do you mainly speak at home?

Response categories

- English
- Spanish
- Chinese
- Some other language (please specify)

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Contact SEER MHOS

Researchers are strongly encouraged to request information and technical support at SEER-MHOS@hsag.com to obtain help understanding the data before making requests and undertaking any analyses.

To stay up to date on the data resource, please join the SEER-MHOS Listserv

