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Division of Regulations Development
Centers for Medicare and Medicaid Services
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Dear Mr. Parham,

The Special Needs Plan Alliance (SNP Alliance) is a national non-profit leadership organization for Special Needs Plans and Medicare-Medicaid Plans. The SNP Alliance represents 26 health plan organizations with over 400 plan products, serving over 2.8 million enrolled beneficiaries (about 60% of all beneficiaries enrolled in SNPs). These special needs plans (SNPs) and Medicare-Medicaid plans are subsets of Medicare Advantage (MA) plans.

A large proportion of the individuals enrolled in SNPs are dually eligible for both Medicare and Medicaid and have high social risk issues, including low literacy, housing instability, food insecurity, and lack of reliable transportation or telephone access. The SNP population also has greater racial and language diversity than the general Medicare population overall. Nationally, dually eligible individuals comprise about 11% of beneficiaries, but account for 30% of costs due to their condition and social risk complexity.

COMMENTS

We have reviewed the CMS memorandum and Supporting Statements A and B and materials Attachment A, B, and C distributed via HPMS and issued in the FR on June 26, 2023, pertaining to changes and field testing of the Health Outcomes Survey instrument.

Basis for Analysis - We base our comment development on virtual meetings and calls held in July with special needs health plans, and re-examination of previous analysis on the Health Outcome Survey, including a recent Issue Brief, co-developed with ATI Advisory ([Ensuring-Equity-and-Fairness-in-MA-Quality-Measurement_Brief_Final.pdf \(snpalliance.org\)](#)) and our White Paper [snpa-paone-hos-white-paper-final-dec-2018-1.pdf \(snpalliance.org\)](#). In preparing our comments, we also reviewed health plan responses over the last several years on items pertaining to the HOS in the SNP Alliance Annual Survey (2017-2022).

OVERVIEW

We applaud CMS' commitment to ensuring that instruments and quality measures used in the Medicare program are valid, reliable, accurate, fair, and have utility to promote improvement. We are encouraged by the willingness of CMS to re-examine the Health Outcomes Survey. We agree with the interest in revising and field testing the HOS instrument. We appreciate the proposed use of items from PROMIS and the GAD-2 screen which could be used to replace current questions around functional status assessment and could add to the understanding of anxiety within the Medicare population. We strongly support the addition of a web-based mode for collection.

However, the proposed field testing falls far short of what is needed in terms of revising and testing the Health Outcomes Survey. The SNP Alliance and other organizations have reviewed, analyzed, and reported on information that indicates the HOS instrument needs a more major overhaul. The methods of measurement and reporting utilizing HOS in the Medicare Advantage quality measurement program likewise need substantial changes in order for this to be used in a way that is fair, equitable, and appropriate. As it exists, HOS cannot be used to generate accurate and reliable results to guide improvement. Conducting a field test of a few items and the response rate from a web-based survey mode versus the traditional way of collecting HOS data is not a good use of resources given the other limitations of HOS.

- ***Further revisions to the Instrument*** - The SNP Alliance strongly recommends additional revisions to the Health Outcomes Survey (see analysis within this letter about the limitations of HOS) beyond those which have been proposed.
- ***Attention to Proposed Analysis & Use*** –HOS is not adequate to be used as the vehicle for performance evaluation of a plan nor for comparisons across plans for the longitudinal measures which currently are based on HOS.

- **Field Testing Modifications** - Field testing is an important step—but only as part of an effort to ensure that the HOS instrument is valid and reliable for all sub-group populations in which it is intended to be used. Unfortunately, there is strong evidence that this is not the case. The HOS instrument (all questions) needs to be part of a field-testing effort, not only the proposed new items.
- **Inaccurate Cost Estimates** – To be useable by the Medicare program and all stakeholders, and to support articulated health equity goals, revisions to HOS and field testing must be more substantive. Even as outlined in the PRA Notice, the cost estimates are substantially under-estimated.

RECOMMENDATIONS

We provide recommendations and offer comments focused in three areas:

- 1) Proposed changes to the HOS instrument
- 2) Methods (design, sampling, analysis)
- 3) Burden/cost estimates

Recommendation #1 – OBTAIN SUBSTANTIVE INPUT FROM AFFECTED

STAKEHOLDERS AS PART OF MORE SUBSTANTIAL REVISIONS TO HOS - The HOS instrument needs more substantial revisions than are being proposed if it is to be used in a fair and equitable quality measurement and reporting system. The whole instrument needs additional review with more stakeholder input from diverse communities for comprehension, format, accuracy, validity, and utility. The proposed revisions are insufficient to address the issues we and others have raised. Please see our Issue Brief, co-authored with ATI Advisory and our SNP Alliance White paper (links provided later in this letter) for additional analysis and information.

Possible Solution – Stakeholder engagement with advocacy and beneficiary groups, special needs health plans, researchers, and others—with structured and facilitated discussions would provide rich qualitative information to guide revisions to the HOS.

Regarding the items being ADDED we have the following comments, examining HOS Version B as a reference:

- New functional status items proposed – Items # 9, 10, 11, 12, 13
Need for Not Applicable or Contextual Response Option - For some of the items around physical activity we recommend including an additional response option indicating that the question either does not apply to the person at the present time or the addition of some kind context for interpreting the response.
 - For example, with Item #10. Climbing 5 flights of stairs is unlikely to be attempted among individuals with recent surgeries, complex chronic conditions,

permanent physical disabilities, or frailty characteristics. Furthermore, many buildings do not have 5 flights of stairs meaning that the person may not be sure of their ability. Individuals do not attempt stair climbing for many reasons such as: (1) fear of falling, (2) difficulty breathing due to heart and lung conditions so not recommended, (3) recent surgery, such as a hip or knee replacement, (4) confinement to a wheelchair, and/or (5) does not live in a building where there are flights of stairs. The person may therefore want to respond: “Not applicable” or “Not recommended given my condition.”

- Item #12 and Item #13 both mention moving furniture (“moving a table,” or “moving heavy furniture”)—Most individuals would not move their own furniture (regardless of their health status) given concern about causing self-injury. We recommend dropping Item #13.
- ***Social Risk Screening*** Items #42 through #53 – We do not recommend adding these items to the Health Outcomes Survey **for purposes of measurement**. Our reasons include:
 - These same social risk issues of housing, food, transportation insecurity already have been added to required social risk screening through the Health Risk Assessment. CMS has already indicated the validated and standardized risk screening survey items that are acceptable for use in the HRA.
 - Likewise, the NCQA already has a measure for social risk screening and follow-up that focuses on these same three risk issues. This NCQA measure is on the pathway to be used in the Medicare Advantage quality measurement system by CMS, as indicated in proposed rulemaking.
 - The items suggested have not been properly validated. The wording of the social risk items based on online interviews with “9 or fewer respondents” is not an acceptable basis for developing a survey item. In other regulatory requirements, social risk screening must be done based on validated tools and items, such as in the PRAPARE or AHC instruments.
 - Since the HOS data is blinded to the health plan and to the provider or support services professionals working with the beneficiary, beneficiary outreach post-completion of HOS is impossible—thus there is no way to trace the experience of the person nor provide follow-up. The addition of these questions could cause confusion within the individual—thinking that by responding to this survey they have now indicated a social risk need which will be reviewed and addressed by their health plan or doctor. Including these items in HOS will not provide information to guide response to the person and could cause harm to the individuals who have vulnerabilities in these areas and might believe or assume that filling out this survey equates with notification of need for help where someone will be responding.

In summary, the social risk items are (1) redundant to other social risk screening requirements and review of practices already in place, (2) are not useful for quality improvement, (3) represent an unnecessary burden on the individual and (4) could cause confusion. We recommend focusing on the Health Risk Assessment requirements both in the Model of Care and in quality measurement and NCQA SRS quality measures underway that address social risk screening and follow-up.

For case mix methodology – To clarify, we have expressed our support for recognizing the importance of social risk factor vulnerabilities among HOS respondents ***for purposes of enhancing the case mix methodology used to analyze the HOS data***. For this purpose, CMS could use dual status as a proxy indicator of high social risk. Dual status as a proxy indicator for high social risk/low socioeconomic status has been recommended by a scientific committee from the National Academies of Science, Engineering, and Medicine in their review of Medicare payment policies for accounting for social risk. They issued a series of five reports (see: [Accounting for Social Risk Factors in Medicare Payment : Health and Medicine Division \(nationalacademies.org\)](https://www.nationalacademies.org/publications/Accounting-for-Social-Risk-Factors-in-Medicare-Payment)). HOS could have a question at the end of the survey (where other demographic characteristics such as age and gender and race appear on the instrument). The individual would indicate dual eligible status (the person would check a box indicating they also are on their state’s Medicaid program in addition to being enrolled in Medicare). Related to this comment, we continue to recommend that CMS support more robust outreach to dual and diverse Medicare beneficiaries so that the HOS respondent sample is inclusive of individuals with these characteristics.

Regarding the items being DELETED, we have the following comments and recommendations for adding items back in as this information is important for collecting population health data and comparing to other datasets about members enrolled in the plan:

- ***LIVES ALONE*** - The item that was in HOS regarding whether the person “lives alone or with others” should NOT be removed. This is an important characteristic, especially given substantial research and practice evidence of an increasing rate of social isolation and lack of family/care partner support among older adults and those with physical disabilities.

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

1 ☐ Alone

2 ☐ With spouse/significant other

3 ☐ With children/other relatives

4 ☐ With non-relatives

5 ☐ With paid caregiver

- ***CONDITIONS*** – The items where the individual indicates their conditions where “a doctor has told you that you had . . .” and “are you currently under treatment for” should be added back in. These questions build the profile of the person which contributes to

understanding their level of complexity. We strongly recommend using the following wording to address important conditions which would substantially impact a person's daily function and prognosis—this is particularly important when considering longitudinal health status:

- Colon, Lung, Breast Prostate Cancer – Recommend that they be listed rather than just “any cancer” –and could include them all in one question which is posed: “Are you currently under treatment for any of the following”
- Stroke or Progressive Neuro-Muscular Condition such as ALS, MS, or CMT
- Alzheimer's disease or dementia
- **PROXY Response** – We strongly recommend that the item indicating if the person had a proxy respondent be added back. This is extremely important for understanding and comparing responses and it is standard practice to separate proxy respondents from self-directed responses. This is particularly important if the respondent was a paid professional caregiver. We do not understand why this was removed.

61. Who completed this survey form?

- 1 ☐ Person to whom survey was addressed → **STOP HERE**
- 2 ☐ Family member or relative of person to whom the survey was addressed → **Go to Question 62**
- 3 ☐ Friend of person to whom the survey was addressed → **Go to Question 62**
- 4 ☐ Professional caregiver of person to whom the survey was addressed → **Go to Question 62**

Recommendation #2 – CONSIDER UTILITY OF THE DATA - HOS Data Insufficient for Comparison and Improvement - SNP Alliance strongly supports obtaining information directly from the beneficiary on his/her/their status and experience of care. However, currently the HOS does not support performance evaluation nor comparison across plans and does not provide information to guide quality improvement.

- *Blinded Respondent Sample Does Not Offer Actionable Information* - Unfortunately, blinded longitudinal data does not offer information that is actionable to a health plan or provider. It would be useful for an individual to discuss their self-report of status, compared to his/her/their self-report of status two years ago, with their provider as part of care conversations—but that is not how HOS is used. Providers are unaware and unable to see who or how their patients have responded to status questions.
- *Biased Sample* - The composition of the respondent pool is inadequate to support the goals of equity, accuracy, and utility. Even if the response rate improves with the use of web-based surveying methods, the respondent sample is heavily biased to White, English-speaking individuals.

Possible Solution - In addition to addressing the sample bias (discussed further within this letter), HOS could be improved by allowing the respondent to provide some kind of *contextual information* about what has happened to them over the past two years—particularly for longitudinal measures. It could have checkboxes or Likert scale questions to provide insight from the individual about what impacts their health status. This would retain anonymity but could help plans know what was driving the health status changes within the respondent sample that reported.

Recommendation #3 – TEST THE WHOLE INSTRUMENT, NOT PIECES/ITEMS

SEPARATELY - A true test of a survey instrument involves the question order, format, length, and total duration to complete--not just each individual item posed separately. Response rate is important, but comprehension of each item and the instrument as a whole (in the way that it is experienced by the respondent) is at least equally important. The response scales may not be equally understood by different sub-population groups. Examining the survey as a whole and the response scale comprehension among diverse population sub-groups should be included in the field testing—especially if CMS wishes to compare two versions of a revised instrument and wishes to understand how comprehension and response may differ based on characteristics of the person completing the survey.

Possible Solution – We recommend revising the instrument more substantively, as noted. However, even in the short-term changes are possible. For example, a series of focus groups and qualitative interviews with ethnically and racially diverse, low-income, disabled, frail, non-English speaking, and complex populations would be helpful to reveal limitations around HOS. Such information would guide CMS to make changes to HOS to better meet health equity goals and to support the principles and standards around measurement tools pertaining to accuracy, validity, reliability, feasibility, and utility.

Recommendation #4 – ATTEND TO CONTRACT SELECTION TO ACHIEVE A DIVERSE

FIELD-TESTING SAMPLE – When ready HOS is for field testing, we strongly advise attention to selecting contracts that include a high proportion of diverse beneficiaries, for example where over 80% of enrollment is dually eligible, disabled or low-income, and where contracts have a substantial enrollment of non-White, non-English speaking individuals. We also recommend selecting a set of contracts that predominately serve frail elderly, and a set of contracts that predominately serve persons with high behavioral health needs and physical disabilities.

- To achieve this, we recommend that at least 50% of the contracts used in the field testing are from SNPs or MMPs—using these contracts, such as 5 FIDE-SNPs, 5 HIDE-SNPs, 5 MMPs, 5 I-SNPs, and 5 C-SNPs (total of 25 contracts). FIDE-SNPs and I-SNPs have a much older and more frail population. HIDE-SNPs and MMPs

have a higher proportion of persons who became eligible for Medicare because of a physical disability and who have a higher rate of behavioral health and mental health conditions. C-SNPs have individuals with specific complex conditions such as HIV/AIDS and will provide important information from a population that has higher rates of functional and emotional health status challenges including anxiety.

Recommendation #5 – SUBSTANTIALLY INCREASE/IMPROVE THE SAMPLE SIZE and COMPOSITION – The sample size and composition for this proposed field test are not adequate. As noted, we recommend that the sample size be substantially increased and diversified through purposeful selection of contracts with high proportion of dually eligible, diverse, and complex individuals. This would allow for oversampling among certain groups--to ensure that persons of color, non-English-speaking persons, and individuals with condition complexity and social risk characteristics are sufficiently represented in this field testing to allow for sub-group analysis.

The volume of responses with just 340 individuals by contract would not be sufficient to conduct statistical analysis to compare Version A and Version B in important sub-populations (e.g., White vs. non-White; Dual vs. Non-Dual; English-speaking vs. Non-English speaking; Elderly vs. Younger Adult). We appreciate that the field test was initially designed simply to compare the respondents from Version A to the respondents from Version B. However, if the composition of the sample is primarily White and not does not have sufficient dual, non-English speaking individuals—then it will be impossible to ascertain whether these individuals differ in their response to Version A or B—due to insufficient data.

See our suggested revisions to the proposed sampling distribution Table 1 that appeared in the Supporting Statement B (next page). We strongly recommend that the sample have enough individuals with these characteristics to support statistical analysis to compare between sub-groups.

The researchers will need to re-calculate/re-determine the following: effect size, confidence level, power, and magnitude of practice significance when they re-calculate the sample size per contract and as a whole. Note that *per contract analysis will be very important*—particularly as purposeful selection of contracts with diverse enrollment characteristics could yield a rich set of information for CMS. This will help ensure that differences may be related to contract--once everyone is combined, those differences are lost in the analysis. See Table 1.

Table 1. Revised Proposed Sampling Distribution within Each Participating Contract (n=?)							
Web-Mail-Phone with Field Test Questionnaire (Experimental Arm)				Mixed Mode (Mail-Phone) with Field Test Questionnaire (Control Arm)			
HOS Field Test Questionnaire Version A		HOS Field Test Questionnaire Version B		HOS Field Test Questionnaire Version A		HOS Field Test Questionnaire Version B	
White	Non White	White	Non White	White	Non White	White	Non White
Non-Dual	Dual	Non-Dual	Dual	Non-Dual	Dual	Non-Dual	Dual
English language	Non English speaking	English language	Non English speaking	English language	Non English speaking	English language	Non English speaking

HOS-M and HOS – Please be sure that the field test sample is pulled from the unused sample frame from BOTH the HOS-M and the HOS. The HOS-M is used for calculating frailty adjusters for some FIDE-SNPs and it would be important to include these respondents as well as those who respond to the full-HOS.

Recommendation #6 – CONDUCT SUB-GROUP ANALYSIS – The Health Outcome Survey must be adequately tested in non-White and non-English speaking individuals and those with low literacy to ensure that the questions and scaled responses are understood and meaningful to these individuals. It is critical to conduct analysis of individuals who are non-White, dually eligible (a proxy for high social risk), and non-English speaking and compare them to individuals who do not have these characteristics. Sub-group analyses must be done. This will inform how/when/if to use HOS with these population. This can be part of a larger effort around HOS to determine if diversity characteristics impact HOS responses. This will be an important step to examine accuracy, validity, feasibility, and utility issues in groups who have a different racial, ethnic, language, literacy, and economic profile than the Veteran population upon which HOS was developed. Proper inclusion of diverse populations in all aspects of development and testing is in keeping with the health equity goals espoused by CMS, HHS, and this Administration.

Recommendation #7 – FULL TRANSPARENCY ON RESULTS – Researchers and CMS must fully report results from qualitative and quantitative examination of HOS and from this field testing. This information is vital to inform future directions for many stakeholders and will be useful beyond the initial purpose of modifying one instrument. The information should be distributed as soon as possible after analysis in keeping with transparency and accountability standards held by the U.S. government. We appreciate CMS’ commitment to informing the

general public and to providing in-depth information to subject matter experts working within the health care, social services, academic, and other related fields.

Recommendation #8 - RECALCULATE BURDEN AND COSTS – The Supporting Statement A indicated expected burden and costs via the hours and wages for conducting the survey once with an estimate of the average time to complete the HOS as 15 minutes at \$28.01 per hour and the only costs included are those of the respondent.

Time to complete HOS is underestimated. We do not agree with the time of 15 minutes, particularly if the respondent completes the full HOS (as recommended) to provide CMS with a much more complete picture of response to the questions on HOS (not only the new ones proposed) ensuring that respondent differences by key characteristics (e.g., race, dual status, primary language) are captured and analyzed. A closer estimate of time would be 60-75 minutes per respondent.

Costs borne by others not shown – The costs to administer the survey, presumably utilizing approved survey vendors that meet the training requirements set by CMS, are not included in the PRA Notice. This may be an oversight—we recommend these costs be made public. This will be important for estimating costs to health plans in the future as the health plan must cover the cost of HOS annual surveying of its members. This is pertinent to determining not only the field testing cost, but the burden going forward—and is in keeping with the intent of the Paperwork Reduction Act.

ADDITIONAL ANALYSIS

The SNP Alliance espouses 11 principles around quality measurement pertaining to special needs populations [Quality and Performance Evaluation - SNP Alliance](#). This includes principles of fairness, accuracy, inclusion, and utility. An important component of measure development and testing is to ensure that individuals who are non-English speaking, non-White, with high social risk and complexity characteristics have equal access and ability to participate in the quality measurement process as persons who do not have these characteristics. Furthermore, this means that the instruments, measures, testing, methods, and analysis of results properly consider these diversity and complexity characteristics and report findings from the analysis so that adequate information is available to interpret scores and to act on results.

HOS History

While widely used and researched, the Medicare HOS was originally developed using a veteran population of primarily older white males. To date, the survey has not been re-validated in diverse populations including those for whom English is not their primary language, those with low health literacy, those with chronic or progressive physical or intellectual disabilities, and among diverse sub-groups of individuals of non-White racial and ethnic cultures. Furthermore,

the HOS is currently available in just three languages for oral administration (English, Spanish and Mandarin). When sub-populations are not adequately represented and/or survey questions do not reflect the experiences of the individuals being surveyed, the risk is that resultant data and assumptions or conclusions from that data may be skewed.




Over the last several years, the SNP Alliance surveyed health plans, analyzed peer-reviewed literature, and gathered information from researchers and experts to better understand the strengths and limitations around use of the Medicare Health Outcome Survey (HOS) in the Medicare Advantage quality measurement system. There is compelling evidence indicating the need for improvement. The challenges are particularly pronounced for special needs plans as they serve diverse, low-income, disabled, and chronic care, complex, or advanced-illness populations. These populations and plans are more likely to be negatively impacted by the limitations in HOS instrument, methods, and scoring.

Limitations discovered include:

- *Diversity of Medicare Population is not fully Considered*
- *Instrument Limitations as Applied to People with Special Needs*
- *Inadequate Methods of Administration*
- *Information Decay, Time Lag*
- *Proxy Challenges*
- *Results May be Affected by Underlying Characteristics of Enrollment*
- *Attribution, Context Issues*
- *Inadequate Models and Adjustments*
- *Cautions Regarding Analysis, Interpretation, and Reporting*

Please refer to our White paper for more information on these limitations [snpa-paone-hos-white-paper-final-dec-2018-1.pdf \(snpalliance.org\)](#). A recent analysis of HOS by ATI Advisory demonstrated that the HOS respondent sample significantly under-represents non-White, non-English speaking individuals (Figure 1).

Figure 1. Demographics of HOS Respondents, Medicare Advantage Enrollees (non-SNP) and SNP Enrollees²

 HOS Respondent	 Medicare Advantage Enrollee (non-SNP)	 SNP Enrollee
79% White	75% White	45% White
10% Non-English Language Spoken at Home	14% Non-English Language Spoken at Home	28% Non-English Language Spoken at Home
0% Over Age 85	11% Over Age 85	9% Over Age 85

HOS respondent data from CMS Cohort 2022 follow-up HOS Respondents. Medicare Advantage data from 2017-2019 MCBS.

Source: [Ensuring-Equity-and-Fairness-in-MA-Quality-Measurement Brief Final.pdf \(snpalliance.org\)](#)

Analysis of the demographic composition for the original instrument and testing also shows a vastly different profile than the SNP population. (Figure 4)

Figure 4. Demographics of MOS and Veterans SF-36 Respondents Compared to Current Medicare Advantage (non-SNP) Enrollees and SNP Enrollees^{ix}

MOS and Veterans SF-36 Survey Respondents	10% Younger than 65	98% Male	19% Non-white	72% Married
Medicare Advantage Enrollee (non-SNP)	11% Younger than 65	44% Male	21% Black or Latinx	53% Married
SNP Enrollee	33% Younger than 65	36% Male	51% Black or Latinx	24% Married

MOS and Veterans SF-36 respondent data from Kazis et al., 2004. Medicare Advantage data from 2017-2020 MCBS.

To further illustrate some of the problems in using HOS for longitudinal data as a source for quality measurement, we provide a more in-depth review of the *Physical Functioning Activities of Daily Living* (PFADL) measure.

The SNP Alliance has long supported a focus on functional status as an important characteristic of people with complex chronic, behavioral, and long-term care needs. Understanding a person's functional status is a very important piece of the puzzle in crafting a tailored response to care. However, this measure does not focus on how a health plan is helping the individual address physical functioning. It does not capture actions to promote performance of activities of daily living.

The PFADL measure is longitudinal. It compares two snapshots of self-report functional status at two-year intervals among a sample of people enrolled in the plan. The PFADL measure is derived from HOS using questions about abilities such as moving tables, or hobbies such as bowling or playing golf. We have frequently discussed the problems with this wording, that is sometimes considered insensitive or lacking relatability to cultural/ethnic diverse or disabled individuals. Many low-income individuals do not have the resources to play golf or go bowling. These examples are potentially confusing to the respondent.

If a health plan, such as a special need plan, has a large proportion of members who are frail, have complex chronic, degenerative, progressive conditions, have high social risk factors and other life events that impact their physical health and their ability to perform activities of daily living—these people will be more likely to have poor physical functioning. Therefore, there will be many more of these individuals present in the random sample of members (HOS sample pulled by CMS). It is predictable given the characteristics of the population.

The wording of the questions used to derive the PFADL measure sets up a pre-emptive bias against beneficiaries who are disabled or have permanent limitations in functions—and against the plans/providers who care for these people.

There are six items that are used to derive the PFADL measure. The question reads:

*Because of a health or physical problem, do you have any difficulty doing the following activities **without special equipment or help from another person**? (bathing, dressing, eating, getting in and out of chairs, walking and using the toilet).*

Such individuals would report that they have substantial limitations and cannot perform these ADLs *without help*. The way the question about six ADLs to derive the PFADL is worded, the beneficiary responding would be limited in reporting only what he/she/they can do on their own.

A person responding who is already permanently disabled or has substantial ADL limitations or progressive neuro-muscular conditions and other frailty indicators and cannot perform one or more of these ADLs without help starts at the lowest end of the scale (“Unable to do”).

However, this does not capture important health plan or provider quality of care inputs and resources provided to the individual – to help them address their condition and permanent physical disabilities so that they can now perform these daily tasks **WITH HELP**, including adaptive equipment, home modifications, etc. Over time, with help from their plan and providers, they may have the ability to perform these ADL tasks, even though their condition is still present.

A key component and action of special needs health plans is to provide long term services and supports and help the individual gain function such as with adaptive equipment –grab bars, a shower bench, a lift chair for the stairwell, special shoe-horn, button-hole tool, etc. as well as personal care assistant for ADLs.

These adaptations and these PCAs are important to the daily life of the person. Such support can result in change where the person is able to perform some of these functions *with help*. However, the HOS question asks the person about performing the task “*without special equipment or help from another person*”—so two years later that individual would again say “Unable to do.”

Even though this person would have improved in ADLs with assistance - where his or her level of function in bathing, dressing, eating or moving is better *with help*—the measure would not capture this change. The point is not that the individual still can’t do the task alone – but that the person can now do something they couldn’t before *because they now receive help*. The HOS question and measure does not account for this.

The difference between being unable to dress or bathe alone and being able to do some of these daily activities with the help of a personal care assistant, shower bench, grab bar, or special shoe-horn—can be life changing and is an important difference to note.

None of this important effort or support is captured in the PFADL measure. Thus, the wording and measure actually close the door to showing improvement in function – among people who have substantial limitations. This does a severe disservice and is not in keeping with the intent of marking change in ADL function.

This is an example of a substantial limitation in HOS. It calls into question the utility of the measure for special needs populations where many members have chronic limitations of activities of daily living and/or are permanently disabled.

Thus, the administrative and beneficiary burden associated with conducting the survey and calculating this measure is high without providing benefit. This is an inequity. It is an example of how the survey needs to be re-examined and re-tooled with purposeful attention to diversity and inclusion and to the value and utility of information that is being collected. In this case, a simple re-wording could be all that is needed to capture important change in the life of the individual.

SUMMARY

In summary, while we are encouraged by CMS' interest in reworking items within the HOS, we strongly support revisions to HOS beyond what has been proposed. We have attempted to offer solutions to addressing some the observed limitations. We offer examples and analysis of why it is so important to do so at this time. We also recommend re-working the methods and cost estimates for field testing. We strongly support field testing a revised instrument among a diverse group of beneficiaries and having an additional web-based mode of administration available.

Thank you for the opportunity to comment. We appreciate your attention. Please let us know if you would like to discuss any of this further. We would be happy to do so.

Sincerely,



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