BARENTS GROUP

KPMG Consulting

Results of Testing OASIS Measures with Consumers

Final Report

PROJECT: CONSUMER TESTING REGARDING PUBLIC DISSEMINATION OF HOME HEALTH CARE QUALITY DATA BASED ON OASIS OUTCOME REPORTS

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EXECUTIVE SUMMARY

Background

In 1987, CMS was mandated to collect and review data about the performance of home health agencies. Now CMS plans to make OASIS-based performance measures available to the public so that consumers can make informed choices among home health agencies based on the quality of care they provide.

Methodology

The Barents team worked with UCHSC to develop plain language versions of the 54 OASIS measures selected for consumer testing. They then conducted interviews with Medicare beneficiaries and their caregivers in order to assess consumer reactions to these measures. The Barents team conducted individual and group interviews with a total of 31 respondents in two market areas: Baltimore, Maryland and Tampa, Florida.

Key Findings

- Although respondents had positive impressions of home health care, most respondents did not completely understand the scope and expected outcomes of home health services. In addition, most seemed to be unaware that they had a choice of home health agencies. Instead they relied almost exclusively on referrals from hospital-based providers. This suggests that the public release of OASIS measures should be accompanied by education about the scope, outcomes, and choices of home health services.

- Most respondents had difficulty relating to OASIS measures as organizational statistics. Instead they tended to evaluate home health quality from a very personal perspective. This limited their ability to use OASIS measures to identify differences in organizational performance and quality of care.

- Consumers expressed the most interest in indicators that were clearly linked with clinical outcomes. They also perceived measures related to patients achieving independence and self-sufficiency as extremely important.

- Categories identified as most important include:
  - "Meeting Basic Daily Needs"- which includes measures of self care
  - "Physical Health"- which includes clinical outcome measures
  - "Getting Around"- which includes measures of mobility

- Within those broad categories, the OASIS measures identified as most important include the following:

- ◊ Healing well after an operation;
- ◊ Getting more bedsores;
- ◊ Getting better at feeding themselves without help;
- ◊ Getting better correctly taking their medicines without help;
- ◊ Needed emergency medical care because of a wound infection or because of a fall or accident at home
- ◊ Getting better at understanding and remembering things without help.

- ♦ Respondents often had difficulty judging outcome measures, because they did not understand standards of care or reasonable expectations for homecare. Respondents with little or no experience with home health care often asked questions about recovery time, expected incidence of adverse events, and expectations regarding specific illnesses.

- ♦ Respondents focused on adverse event outcomes when they were asked to look at measures that they would use to choose a home health care agency. While measures that showed improvement were very important to consumers, the measures that showed decline in health were flagged by respondents as critical information to consider when making a decision about which provider to use. Nevertheless, other respondents felt it was not fair to hold home health agencies accountable for all adverse outcomes, such as unexpected deaths, because sometimes they were inevitable even with the best of care.

BACKGROUND

The Omnibus Budget Reconciliation Act of 1987 mandated that HCFA (now CMS) monitor the quality of home health care and services with a standardized assessment instrument for collecting and reporting information on all patients receiving home health services. To fulfill this mandate, HCFA contracted with the Center for Health Services Research at the University of Colorado Health Sciences Center (UCHSC) to create the Home Health Outcome and Assessment Information Set (OASIS) in 1990.[1] Home health agencies use OASIS to collect information about patients' health, functional status, health service use, living conditions, and social support needs. This research eventually produced numerous outcome measures, including adverse event, end-result, and utilization outcome measures. CMS now plans to make OASIS-based performance measures available to the public so that consumers can make informed choices among home health agencies based on the quality of care they provide.

Although prior research conducted by Barents identified some of the attributes that consumers currently equate with quality in home health services (including reliability, trustworthiness, caring, and communication)[2], consumers' responses to evidence-based quality measures such as those included in OASIS have not been assessed. CMS asked the Barents team to work with UCHSC to develop plain language versions of the 54 measures to test with Medicare beneficiaries and their caregivers in order to better enable consumers to understand and use the information for evaluating home health agency performance. (See Appendix I for a complete list of the OASIS measures and Appendix II for "plain language versions" of these measures)

Research Goals and Objectives

The purpose of this research was to evaluate the plain language versions of the OASIS measures described above. Specific research questions include

- Which measures are most important to consumers? Do consumers respond more readily to measures reflecting negative outcomes or adverse events, or to measures reflecting improved functional status?
- Which measures do they readily understand? Which ones do they find confusing?
- What factors would motivate consumers to seek out and use information on the performance and quality of home health agencies?
- How do these measures relate to consumers' current perceptions of home health quality?

[1] Center for Health Services Research, "*Supporting Document 1: Chronology of Major Research and Policy Events Influencing the Outcome-Based Quality Improvement Initiative."* November, 2001.
[2] Barents Group, *"Quality Measurements for Home Health Care."* Submitted to CMS, November 6, 2001.

METHODOLOGY

Prior to testing the 54 OASIS measures with consumers, the Barents team (under separate funding) developed plain language versions of the measures with input from team members at UCHSC and CMS. The Barents team used the "Writing and Designing Print Materials for Beneficiaries: A Guide for State Medicaid Agencies"[3] by Jeanne McGee and the "Assessment of the Nursing Home MDS Performance Measures: How Easy Are They for Consumers to Understand and Use?"[4] report by McGee & Evers Consulting, Inc. as guides and models for rewriting and categorizing the measures. Plain language versions of the measures were subjected to the Fry method (a reading level test) to ensure appropriate reading level.

The Barents team grouped these 54 measures into eight categories, in order to facilitate testing of the full spectrum of measures in single interviews. These categories were as follows:

Category Names	***Topic Area***
♦ "Meeting Basic Daily Needs" ♦ "Doing Household Chores" ♦ "Getting Around"	Activities of Daily Living
♦ "Physical Health" ♦ "Mental Health" ♦ "Staying at Home Without Home Care"	Outcomes
♦ "Having a Medical Emergency While on Home Health Care" ♦ "Patients Whose Health Got Worse on Home Care"	Adverse events

Prior to the second round of interviews, the Barents team drafted descriptions that explained the content and significance of these categories. These descriptions and categories were also rewritten in plain language and tested for appropriate reading level, and were reviewed by

[3] "Writing and Designing Print Materials for Beneficiaries: A Guide for State Medicaid Agencies" by Jeanne McGee, McGee & Evers Consulting, Inc., October 1999.

[4] "Assessment of the Nursing Home MDS Performance Measures: How Easy Are They for Consumers to Understand and Use?", Response to Centers fro Medicare and Medicaid Services (CMS) TDL #5 for Ketchum TO #2: Consumer Language Nursing Home Minimum Data Set (MDS) Performance Measures, Prepared for Barents Group of KPMG Consulting, Inc. by Jeanne McGee, PhD, and Mark Evers, PhD, McGee & Evers Consulting, Inc., Vancouver, Washington, November 7, 2001.

UCHSC and CMS to ensure that they accurately represented the measures (See Appendix III for the categories and descriptions tested.)

Professional research facilities recruited respondents using a standard screening process designed to ensure variations across gender, ethnicity, age, educational attainment, experience with home health services and non-professional caregiving. All respondents were either Medicare beneficiaries or non-professional caregivers for Medicare beneficiaries, and all respondents had at least some high school education (See Appendix VII for further details regarding respondent characteristics). Recruitment screeners were developed for each test site with input from CMS and UCHSC personnel (See Appendices IV and V for Recruitment Screeners).

The Barents research team conducted a combination of individual in-depth interviews and small-group interviews to assess consumers' understanding of and interest in the proposed OASIS measures. Interview guides were designed to test the salience of the measures and matching categories to consumers' understanding of home health quality. Barents Group developed the interview guides with immediate input from UCHSC and CMS during the first round of interviews and revised the guides further between the first and second rounds of testing (See Appendix VI for Interview Protocol). The research team conducted interviews with a total of 31 respondents in two markets: Baltimore, Maryland and Tampa, Florida. Respondents were diverse in terms of age, race, education, and home health experience. Ten respondents had received home health services themselves, eight were caregivers whose loved ones had received home health care services, and thirteen respondents had no home health experience at all. Interviews provided valuable information regarding consumers' comprehension of the measures, their understanding of home health and indicators of home health quality, and their information preferences. (See Appendix IV for further information on participant characteristics.)

All respondents signed consent forms informing them that participation was voluntary, that the interviews would be audio- and video-taped, and that all responses were confidential. Each respondent was paid a $75 honorarium for participating in a 1-½ hour interview.

KEY FINDINGS

- **Positive impressions of home health services**
  Consumers associate home health care with positive concepts, such as comfort and caring. They see home health care as a preferable alternative to going to a nursing home. As one respondent commented, "If you can be taken care of at home, this is much better than having to go to nursing home." Another said, "Home is familiar and a better place to be when someone is sick or is having surgery and needs some help." A third respondent described home health services as "welcome assistance."

- **Incomplete understanding of the scope and purpose of home health services**
  Findings from the in-depth interviews in Baltimore, MD and Tampa FL suggest that most Medicare beneficiaries and their caregivers are unfamiliar with the scope of home health care services. For example, many were surprised to learn that home health care includes speech therapy, mental health assessment and referrals, and home inspections to prevent falls and accidents. Other respondents did not seem to distinguish home health care from hospice care.

- **Consumers focus on individual experience, not on statistics about organizations**
  Most respondents assess quality from a personal perspective, asking questions such as: Do home health workers show up on time? Are they friendly, caring, and competent caregivers? Respondents have difficulty making the transition from thinking about individual needs and services to aggregate measures of agency performance. This affects the importance they attach to particular categories and measures.

- **Limited awareness of choice and limited involvement in selecting a home health agency**
  Most respondents, even those with homecare experience, are not aware that they have a choice in selecting home health agencies. They assume, instead, that the doctor or hospital arranges whatever home health services are needed. Most indicated that they relied either on a doctor's recommendation or on other factors related to reputation – e.g., picking a homecare agency affiliated with a respected hospital.

  Respondents with home health experience indicated that they had little or nothing to do with the selection of the home health agency. As with nursing homes, respondents rely on intermediaries when making home health decisions. Indeed, they seem to rely almost exclusively on referrals they receive while in the hospital. This suggests that doctors and discharge planners are key intermediaries who influence consumers' perceptions of quality and their information-seeking behaviors.

- **Questions about attributing outcomes to home health agencies**
  Many respondents questioned to what extent home health agencies could be held accountable for the patient's safety or recovery. Many noted that the home health care agency could not be responsible for the patient 24 hours a day. For example, some respondents did not think that the home health agency should be blamed for falls, accidents, or unexpected deaths if they occurred while the home health worker was "off-duty." This was a particular concern

when the home health agency was caring for people with chronic, debilitating or terminal illnesses.

- **Questions about other indicators of home health quality**
  Respondents wanted more information about home health agencies in order to assess their quality of care. For example, they wanted to know about the credentials of home health staff, the facility's accreditation status, and about the history of complaints. Others asked about standards by which to judge the performance of the agency, -- for example, the average length of time it ought to take for patients to recuperate while on home health care services.

  Many respondents judged the quality of the home health agency by the apparent skills, qualifications, and personal characteristics of the individual home health worker. For example, they stressed the importance of having staff that is trustworthy, patient, and respectful of the patient's privacy and dignity. They stressed that home health workers should be nurturing, cheerful, and able to provide physical comfort. Others valued home health staff's ability to teach and motivate the patient and caregiver to do their physical therapy and use special medical equipment. Continuity of staff from visit to visit was also noted as an important element of high quality care.

- **Independence and autonomy as most important outcome of home health care**
  Many respondents said that the ultimate goal of home health is to enable patients to become as self sufficient and independent as possible. As one said, "Being your own boss is important." The OASIS measures that were perceived as most closely linked to self-sufficiency were perceived as the most important.

- **Respondents perceive certain key measures as logically prior to others**
  Respondents often revealed a hierarchy of needs when choosing the most important measures. Many selected measures in a logical order. For instance, respondents chose the measure, "bathing self without help" before "dressing self," rationalizing that bathing comes before dressing. Others noted that measures related to taking medications were crucial, because they affect many other outcomes, such as mental health, mobility, and healing well after surgery.

- **Respondents' information preferences often change when thinking in terms of agency performance, rather than individual experience**
  Most respondents initially expressed greatest interest in measures related to patients' independence and day-to-day functioning. However, when they were prompted to think in terms of agency performance – that is, what they would want to know about an agency ahead of time – many reconsidered their initial responses and began to attach more importance to negative measures, such as getting worse, or to adverse events. However, it was difficult for respondents to shift their focus from the individual patient experience to more "population-based" measures of performance.

- **Preference for individual measures of performance with clear clinical implications**
  When queried about individual measures of performance within categories, most respondents gravitated towards those with clear clinical implications. For example, taking medicines

correctly, feeding oneself, healing well, (preventing) bedsores, were considered more important than grooming or housekeeping.

RESPONSE TO SPECIFIC OASIS MEASURES

- **"Meeting Daily Needs"**
  Almost all respondents identified "Meeting Daily Needs" as the most important category. This category includes OASIS measures related to self-care, including bathing, feeding, dressing, and grooming. Many indicated that everything else hinged upon this category. As one said, "If you can get dressed and bathe yourself and fix meals, then you are self-sufficient and can do everything else, like talk on the phone."

  Within this category, the following items were perceived as most important:

  - ◊ "Getting better at correctly taking their medicines (by mouth) without help"
  - ◊ "Getting better at bathing themselves without help"
  - ◊ "Getting better at feeding themselves without help"

  Within the "Meeting Daily Needs" category, there were two items related to speech and communication. None of the respondents selected these measures as most important, and very few even commented on them. The few that did were confused because they did not understand how home health agencies could improve patients' speaking abilities. They assumed that patients improvement in talking and communicating would come normally and naturally if the patient were improving in other areas, such as taking medications. This suggests that more explanation is needed about how home health can include speech therapy.

  Respondents expressed very little interest in grooming, except as a possible indicator of emotional well-being. They did not differentiate between measures for dressing the upper and lower body.

- **"Physical Health"**
  Most respondents regarded measures in this category as very important. Indeed, improving physical health was perceived to be the primary purpose of home health agencies and a tangible measure of improvement and overall effectiveness of home health care. As one respondent pointed out, a patient's progress after an operation could be a very good indicator of how well the home health staff are tending to patients' needs.

  Within this category, the following item was perceived as most important:

  - ◊ "Healing well after an operation"

  On the other hand, respondents had difficulty with other indicators in this category. For example, several respondents questioned home health agencies' ability to do anything about incontinence or shortness of breath. Other indicators, such as urinary tract infections, were seen as transitory phenomena that a doctor should treat.

- **"Getting Around"**
  Many respondents selected "Getting Around" as one of the most important categories, because it is so critical to performing other important activities of daily living, such as going to the toilet and bathing. Respondents frequently emphasized that patients need to move around on their own in order to achieve independence and self-sufficiency. A few also noted the connection between mobility and mental health, saying that moving around will make you feel better.

  Within this category, the following items were perceived as most important:

  - ◊ Getting in and out of bed without help
  - ◊ Getting better at getting to and from the toilet without help

  Some respondents stated that "having less pain when moving around" was less important, because they believed that the agency could not help or prevent pain.

- **"Doing Household Chores"**

  Response to this category was mixed. Some respondents suggested that doing household chores was an indicator of self-sufficiency and independence. Many others, however, noted that patients could hire someone to help them with these tasks or rely on their families for help. Many also commented that even healthy people do not do household chores regularly.

  That being said, the following items were perceived as most important within this category:

  - ◊ "Getting Better at Fixing or Reheating Light Meals or Snacks"
  - ◊ "Getting Better at Doing Light Housekeeping such as Dusting or Wiping the Table Without Help"

- **"Staying at Home Without Home Care"**

  Many respondents recognized that this category was the goal and ideal outcome of home health care. However, they rarely selected it as one of the most important indicators. Indeed, respondent comments indicated that they did not understand how this category could be used to evaluate a home health agency's ongoing performance.

  Some respondents were confused and disturbed by items in this category relating to people who no longer receive home health care but still need assistance with wound care, medications, or other activities of daily living. Others responded negatively, seeing these items as indications of neglect, and were troubled by the thought that home health agencies would abandon patients still needing help.

- **"Patients Who Got Worse on Home Care"**
  This category, too, evoked mixed reactions. While all respondents expressed concern about patients with declining health, some respondents did not see how home health agencies could be held responsible if patients failed to improve. As one said, "Home health care should

work, but to get worse is only a natural thing to happen when you're on the downside." Some respondents thought this measure referred to patients who were terminally ill or noncompliant. As one respondent said, "The home health care staff can only do their part, and the rest is up to the patient. There is not much more that you can do for these people."

When prompted to think in terms of aggregate measures of agency performance, however, some respondents understood that adverse outcomes could be used to judge the quality of the home health agency.

Respondents who had negative experiences with home health agencies were particularly interested in this category. For example, a respondent whose mother had been seriously injured while receiving home health services thought this category could help consumers identify home health agencies that neglect their patients.

Within this category, the following items were perceived as most important:

- ◊ "Getting more bed sores" was frequently identified as the most important item in this category, because respondents recognized that it indicated negligence on the part of the home health worker.

- **"Having a Medical Emergency While on Home Health Care"**
  Many respondents understood the "medical emergency" category in terms of an agency's response to a medical emergency (e.g., calling 911, administering CPR or first aid), rather than in terms of prevention. Here, again, they did not readily understand that emergencies were something that might be avoided, with proper care. As with other negative measures, however, some respondents began to regard these measures as important when they were prompted to think in terms of prevention and overall agency performance.

  Respondents had a mixed response to the measure "Died unexpectedly." Some said that they would be concerned if one home health agency had a much higher rate of unexpected deaths than all other agencies in the area. However, others thought that it was not fair to hold the home health agencies accountable for all unexpected deaths. One person, for example, said, "This can happen with the best of care." Another noted, "This is a physical thing and you expect people to die if they are this bad off."

  The item most frequently identified as most important was the following:

  - ◊ "Needing emergency medical care because of a fall or accident at home, wound infection, medication problems, or problems with diabetes."

- **"Mental Health"**
  This category was frequently misunderstood. Many respondents did not understand how home health agencies would treat problems related to mental health. Some respondents immediately associated this term with Alzheimer's disease, dementia, and other neurological disorders perceived as untreatable. Another respondent misunderstood the item "Being less anxious," thinking it referred to patients who were "anxious to get better." Others implied

the mental health measure was superfluous, because it could be addressed by taking medications.

Many respondents noted that if a patient had serious behavior problems, such as yelling, hitting, and getting lost, they should be referred to a hospital or nursing home where they could get 24-hour supervision. They did not think that it was realistic to expect a home health agency to provide services for those with severe mental illness. Others suggested that patients' mental health status would improve naturally as their bodies healed and they became more mobile.

On the other hand, a few respondents selected this as the most important category, because they felt that a patient's mental health directly affected their physical well being and their motivation to take care of themselves. Finally, several respondents suggested that this category should include measures relating to depression, because they perceived that to be a common problem among the elderly.

Within the category of mental health, many respondents felt that the most important item was

◊ "Getting better at understanding and remembering things without help"

IMPLICATIONS FOR PUBLIC REPORTING

These findings highlight some key opportunities and challenges regarding the public reporting of home health performance data.

First, consumers' positive impressions of home health and aversion to nursing homes can make the information about home health agency performance appealing. Additionally, consumers may be motivated to investigate home health agencies, because they want to be sure that workers entering their homes and touching their bodies are trustworthy, caring, and respectful.

Secondly, our results indicate that consumers need more education about the scope and expected outcomes of home health services before they can fully benefit from a quality reporting effort. Currently, most consumers seem to underestimate the range of home health services and their potential effectiveness. Without a more complete understanding of what home health agencies can do to improve their patients' health, consumers are unlikely to understand the utility of comparative performance data. Instead they are likely to attribute differences in outcomes to patient characteristics, such as noncompliance, or to factors beyond the home health agency's control, such as terminal illness.

Next, consumers also need to be informed that they have a choice of home health agencies. Our results suggest that most consumers are not actively involved in the process of selecting a home health agency. Most seem to rely exclusively on referrals and recommendations from doctors or other hospital-based providers. In future studies, it may be worth considering conducting research with hospital discharge planners, since they have such an impact on consumers' choices.

Fourth, our findings also suggest that most consumers are unaware that home health agencies can and do vary in terms of their performance. This, too, can diminish the perceived usefulness of investigating home health quality before making a selection. Otherwise, as in the case of nursing homes, consumers are more likely to see the performance indicators as things to monitor when receiving home health care, rather than as quality indicators to be reviewed before selecting a home health agency.

Fifth, our results suggest that consumers are interested in a limited number of measures that have a clear impact on the patient's health and independence. While one cannot draw conclusive lists of preferred measures from qualitative research, our findings suggest that a few core measures across all categories provide respondents with the information they deem important. The remaining measures seem to be superfluous to respondents by comparison. These core measures include the following:

- Healing well after an operation;
- Getting more bedsores;

- Getting better at feeding themselves without help;
- Getting better at correctly taking their medicines (by mouth) without help;
- Needed emergency medical care because of a fall or accident at home, a wound infection, medication problems or problems with diabetes or blood sugar;
- Getting better at understanding and remembering things without help.

Finally, one of the major challenges of public reporting is that consumers do not necessarily attribute health care outcomes to the home health agencies. Instead they assume that most patients get better naturally, and if they do not, the home health agency can do little to bring about their recovery or to prevent their death. Therefore, it was not fair to hold home health agencies accountable for these outcomes. This finding suggests that consumers would question the relevance of comparative performance data that was not case-mix adjusted. However, explaining case-mix adjustment in terms that the average consumer can understand is a challenge in itself.

Next Steps

These results indicate that some of the OASIS measures need to be revised to improve their comprehension and relevance to consumers. Specifically,

- Rename the mental health category and consider separating items related to cognitive functioning from items related to emotional and behavioral problems.
- Explore the possibility of including an OASIS measure related to depression (such as M0590 and/or M0600) within the mental health category.
- Reduce redundancy of some of the measures by combining interrelated items such as dressing and grooming and combining multiple measures regarding taking medications.

APPENDIX I: OASIS MEASURES SELECTED FOR CONSUMER TESTING

OASIS MEASURES SELECTED FOR TESTING

1. Improvement in eating
2. Improvement in dressing upper body
3. Improvement in dressing lower body
4. Improvement in toileting
5. Improvement in bathing
6. Stabilization in bathing
7. Improvement in grooming
8. Stabilization in grooming
9. Improvement in management of oral medications
10. Stabilization in management of oral medications
11. Improvement in light meal preparation
12. Stabilization in light meal preparation
13. Improvement in laundry
14. Stabilization in laundry
15. Improvement in shopping
16. Stabilization in shopping
17. Improvement in housekeeping
18. Stabilization in housekeeping
19. Improvement in ambulation/locomotion
20. Improvement in transferring
21. Stabilization in transferring
22. Improvement in speech or language
23. Stabilization in speech or language
24. Improvement in phone use
25. Stabilization in phone use
26. Improvement in pain interfering with activity
27. Improvement in dyspnea
28. Improvement in number of surgical wounds
29. Improvement in status of surgical wounds
30. Improvement in Urinary Tract Infection
31. Improvement in Urinary Incontinence
32. Improvement in Bowel Incontinence
33. Improvement in Behavioral Problem Frequency
34. Improvement in Cognitive Functioning
35. Stabilization in Cognitive Functioning
36. Improvement in Confusion Frequency
37. Improvement in Anxiety Level
38. Stabilization in Anxiety Level
39. Any emergent care provided
40. Acute care hospitalization
41. Emergent care for injury caused by fall or accident at home
42. Emergent care for wound infections, deteriorating wound status
43. Emergent care for improper medication administration, medication side effects
44. Emergent care for hypo/hyperglycemia

45. Development of urinary tract infection
46. Increase in number of pressure ulcers
47. Substantial decline in 3 or more activities of daily living
48. Substantial decline in management of oral medications
49. Unexpected nursing home admission
50. Unexpected death
51. Discharged to community
52. Discharged to the community needing wound care or medication assistance
53. Discharged to the community needing toileting assistance
54. Discharged to the community with behavioral problems

APPENDIX II: OASIS MEASURES IN PLAIN LANGUAGE[5]

[5] This is the final version of the measures, which reflects the edits made in response to respondent feedback from previous rounds of interviews.

MEETING BASIC DAILY NEEDS

After receiving home health care, the percent of patients who are:

Getting better at feeding themselves without help

Getting better at dressing themselves without help

Getting better at bathing themselves without help

Getting better at combing their hair, brushing their teeth, and washing their face and hands without help

Getting better at correctly take their medicines (by mouth) without help

Getting better at dressing their upper and lower body without help

Getting better at speaking more clearly and being understood without help

Getting better at using the telephone without help

MEETING HOUSEHOLD NEEDS

After receiving home health care, the percent of patients who are:

Getting better at fixing or reheating light meals or snacks without help

Getting better at doing laundry without help

Getting better at shopping in a store or by phone without help

Getting better at doing light housekeeping such as dusting or wiping the table without help

GETTING AROUND

After receiving home health care, the percent of patients who are:

Getting better at walking or moving around using less equipment such as a cane, walker, or wheelchair

Getting better at getting to and from the toilet without help

Getting in and out of bed without help

Having less pain when moving around

PHYSICAL HEALTH

After receiving home health care, the percent of patients who are:

Short of breath less often

Healing well after an operation

Experiencing a bladder or urinary tract infection

Cured of a bladder or urinary tract infection

Having less of a problem with urinary incontinence or wetting themselves

Having less of a problem with uncontrollable bowel movements

MENTAL HEALTH

After receiving home health care, the percent of patients who are:

Having less behavior problems such as yelling, hitting or getting lost

Getting better at understanding and remembering things without help

Confused less often

Having less anxiety

MEDICAL EMERGENCIES

After receiving home health care, the percent of patients who:

Needed emergency medical care because of

-a fall or accident at home,
-wound infection,
-medication problems or
-problems with diabetes or blood sugar

Died unexpectedly

Had to be admitted to the hospital

Needed to go to a nursing home unexpectedly

STAYING AT HOME WITHOUT HOME CARE

After receiving home health care, the percent of patients who:

Can stay at home and take care of themselves at home after getting home care

PATIENTS WHOSE HEALTH GOT WORSE ON HOME CARE

After receiving home health care, the percent of patients who are:

Getting worse at doing everyday things, such as getting dressed, washing themselves, and using the toilet

Getting worse at bathing themselves

Getting worse at combing hair, brushing teeth, and washing face and hands

Getting worse at correctly taking medicines (by mouth)

Getting worse at fixing light meals or snacks

Getting worse at doing laundry

Getting worse at shopping in the store or by phone

Getting worse at doing light housekeeping such as dusting or wiping the table

Getting more bedsores

Getting worse at understanding and remembering things

Getting more anxious than they have been

No longer getting home care but still need services such as

-help to take care of wounds,
-help to correctly take medications,
-help to use the toilet, or
-help with behavior problems such as yelling, hitting, or getting lost

APPENDIX III: CATEGORIES WITH SIMPLE EXPLANATIONS[6]

[6] This is the final version of the categories, which reflects the edits made in response to respondent feedback from previous rounds of interviews.

MEETING BASIC DAILY NEEDS

What does this tell you?

This shows how many patients of a home health care agency are getting better at taking care of themselves. This includes being able to feed themselves, get dressed, and take medications on their own.

Why is this information important?

One of the major goals of home health care is to help people stay in their own homes for as long as possible. When people are no longer able to take care of themselves, their health will decline, and they may need to go to a hospital or nursing home.

DOING HOUSEHOLD CHORES

What does this mean?

This shows how many patients of a home health care agency are getting better at doing basic household chores on their own. These include light chores like fixing small meals, doing laundry, and dusting.

Why is this information important?

Doing household chores keeps the home clean and safe. Home health staff should help their patients get well enough to do some basic chores on their own, so that the patient can stay at home safely.

GETTING AROUND

What does this tell you?

This shows how many patients of a home health care agency are getting better at moving around on their own or by using a cane, walker, or wheelchair. This includes getting better at getting in and out of bed, going to the bathroom, and moving around with less pain.

Why is this information important?

It is important for home health care patients to move around on their own. Moving around keeps people healthy. Home health staff should encourage their patients to be active so they can stay at home as long as possible.

PHYSICAL HEALTH

What does this tell you?

This shows how many patients of a home health care agency have improved health. It includes patients who are healing well after surgery, those having fewer problems with incontinence (wetting themselves or soiling themselves), and those who are short of breath less often.

Why is this information important?

Home health care can improve a patient's health. Patients who get better can stay in their own home.

MENTAL HEALTH

What does this tell you?

This shows how many patients of a home health care agency have fewer mental health problems, such as being anxious or confused, or who have fewer behavior problems, such as yelling or hitting.

Why is this information important?

Patients with mental health problems need help so that they can stay at home safely. Home health staff can help patients who are feeling anxious or confused to get the medications and treatment they need. Home health staff can also help patients with dementia or Alzheimer's disease live at home safely.

HAVING A MEDICAL EMERGENCY WHILE ON HOME HEALTH CARE

What does this tell you?

This shows how many patients of a home health care agency have suddenly gotten worse and have had to go to the emergency room, hospital, or nursing home. It also shows the number of home health patients who died unexpectedly.

Why is this information important?

Many medical emergencies can be prevented. If a lot of patients have unexpected medical emergencies, that may be a sign that the home health care agency is not doing their job well.

STAYING AT HOME WITHOUT HOME CARE

What does this tell you?

This shows how many patients of a home health care agency can take care of themselves at home after getting home health care services.

Why is this information important?

Most home health patients want to stay in their homes and be more independent. Home health staff can help patients to get better at living on their own.

PATIENTS WHO GOT WORSE ON HOME CARE

What does this tell you?

This shows you how many patients of a home health care agency got worse while on home care. It includes people who no longer can bathe or dress themselves, take their medications, or do household chores on their own. It also includes patients who no longer get home care but still need services, such as wound care, mental health services, or help using the toilet.

Why is this information important?

Not all home health patients get better. Some get worse because they did not get the right care. Others get worse because their sickness cannot be cured. It is important that the home health staff do everything possible to help all patients get better.

APPENDIX IV: RECRUITMENT SCREENERS

SCREENER TO SELECT PARTICIPANTS FOR COGNITIVE INTERVIEWS IN BALTIMORE, MD

Participants: Medicare beneficiaries and their nonprofessional caregivers (see below)
Location: Baltimore, MD
Date: February 28 and March 1, 2002
Project: Consumer Testing of Home Health Care Measures, OASIS

Please recruit to ensure 15 interview participants

Criteria:

- Men and Women **(as close to 50% of each as possible)**
- Ages 65-74 and75+ **(as close to 50% of each as possible)**
- African Americans, Caucasians, and other ethnicities who read and speak English **(recruit a mix)**
- Participants with less than a high school diploma, high school diploma or some college **(seek a range across education categories in Q4 below)**
- Medicare Beneficiaries that have received some home health care related service in the past 3 years **(recruit 5, if possible)**
- Non-professional caregivers of beneficiaries that have received some home health care related services in the past 3 years **(recruit 5, if possible)**
- Non-professional caregivers under the age of 65 of any beneficiaries that **have not** received home health care services in the past 3 years **(recruit 2, if possible)**
- Medicare Beneficiaries that **have not** received home health care services in the past 3 years **(recruit 3, if possible)**
- Participants **should not** currently work for a home health agency or be a (retired) doctor, nurse, or employee of a Federal Government Health Agency.

Hello. My name is _____ and I'm calling from [company name], a local research firm. We are conducting a study about home health care information. If you qualify for this study, you would be asked to come to our facility to give your opinions in an individual interview that would last about an hour and a half to two hours.] You will be compensated for your time and we are not trying to sell you anything. Your opinion will help us greatly toward understanding how to provide improved health care information for people age 65 and older. May I ask you a few questions?

[Record respondents' sex. Confirm if any question: *And you are (female/male?)*]

_____ Female
_____ Male

Please identify where you fall within the following age ranges?

_____ Under 65 **[1. Ask if they are a caregiver who assists a family member or friend who is 65or older (Medicare Beneficiary) with their health care decisions on a regular basis. If no to this question, thank respondent for their time and end call. If yes, go to question 2.]**

_____ Between 65 and 74
_____ 75 or older

[Ask respondents 65 and older if they deal with their own health care decisions or if they have someone who helps them. If they deal with their health care decisions, go to question If they have help, ask for the helper's contact information and attempt to call them as a potential caregiver interview. Thank respondent for their time and end call.]

Are you a Medicare beneficiary or a caregiver of a Medicare beneficiary?

_____ Yes **[If yes, go to question 4]**

_____ No **[If no, thank respondent for their time and end call.]**

Do you currently (or have you ever) work(ed) for a home health service, are you a doctor or nurse, are you a current or retired employee of a Federal Government Health Agency?

_____ Yes **[If yes, thank respondent for their time and end call.]**

_____ No [**If no, go to question 5.]**

What is your race or ethnicity? **[Do not read answers.]**

_____ African American (not of Hispanic descent)
_____ White Non-Hispanic
_____ Hispanic
_____ Native American/American Indian
_____ Asian or Asian American
_____ Other (please specify _____

What was the last grade you completed? [Seek a range]

____ 3rd grade or less **[thank respondent and end call]**
____ 4th-8th grade
____ 9th –12th grade, High School Diploma or GED, Technical or Trade School
____ Some College

____ College Graduate, Graduate School **[thank respondent and end call]**

5. *Have you [or the person you care for] received any home health care services in the past three years?* **[Examples, if needed, include: durable medical equipment, skilled nursing care, and homemaking services.]**

_____ Yes **[Go to Invitation]**
_____ No **[Go to Invitation]**

Invitation:

Thank you for answering my questions. You are eligible to participate in the individual interview about medical care information. It will last about one and a half to [two] hours and you will be paid $50 for your time. Your experience and opinions are very important to us. During the discussion we will be speaking in English and reading some print materials, so it is very important that you are comfortable speaking and reading English.

Are you comfortable speaking and reading English?

❑ ***Yes***

❑ ***No*** *[Thank respondent and end call.]*

The interview will be held on _____ at _____.

Can you attend?

_____ ***Yes***
_____ No **[Thank respondent for their time and end call.]**

Could I please have your address so that we can send you a confirmation letter and a map?

If you need glasses for reading, please bring them with you for your interview. Thank you.

SCREENER TO SELECT PARTICIPANTS FOR COGNITIVE INTERVIEWS IN TAMPA, FL

Participants: Medicare beneficiaries and their non-professional caregivers (see below)
Location: Tampa, FL
Date: March 25-26, 2002
Project: Consumer Testing of Home Health Care Measures, OASIS

Please recruit to ensure 15 interview participants according to the following breakdown:

5 Medicare beneficiaries without home health care experience, 5 Medicare beneficiaries with home health care experience, and 5 caregivers of Medicare beneficiaries who are 75+ and have either had experience with home health care or have not had home health care and anticipate needing it in the future.

Criteria:

- Men and Women **(as close to 50% of each as possible)**
- Ages 65-74 and75+ **(as close to 50% of each as possible)**
- African Americans, Caucasians, and other ethnicities who read and speak English **(recruit a mix)**
- Participants with less than a high school diploma, high school diploma or some college **(seek a range across education categories in Q5 below)**
- Medicare Beneficiaries that have received some home health care related service in the past 3 years **(recruit 5, if possible)**
- Non-professional caregivers of beneficiaries that have received some home health care related services in the past 3 years **(recruit 3, if possible)**
- Non-professional caregivers under the age of 65 of any beneficiaries that **have not** received home health care services in the past 3 years, but may anticipate receiving home health care services in the future **(recruit 2, if possible)**
- Medicare Beneficiaries that **have not** received home health care services in the past 3 years **(recruit 5, if possible)**
- Participants **should not** currently work for a home health agency or be a (retired) doctor, nurse, or employee of a Federal Government Health Agency.

Hello. My name is _____ and I'm calling from [company name], a local research firm. We are conducting a study about home health care information. If you qualify for this study, you would be asked to come to our facility to give your opinions in an individual interview that would last about an hour and a half to two hours. You will be compensated for your time and we are not trying to sell you anything. Your opinion will help us greatly toward understanding how to provide improved health care information for people age 65 and older. May I ask you a few

questions?

[Record respondents' sex. Confirm if any question: *And you are (female/male?)*]

_____ Female
_____ Male

1. *Please identify where you fall within the following age ranges?*

   _____ Under 65 **[Ask if they are a caregiver who assists a family member or friend who is 65 or older (Medicare Beneficiary) with their health care decisions on a regular basis. If no to this question, thank respondent for their time and end call. If yes, go to question 2.]**

   _____ Between 65 and 74
   _____ 75 or older

[Ask respondents 65 and older if they deal with their own health care decisions or if they have someone who helps them. If they deal with their health care decisions, go to question 2. If they have help, ask for the helper's contact information and attempt to call them as a potential caregiver interview. Thank respondent for their time and end call.]

2. *Are you a Medicare beneficiary or a caregiver of a Medicare beneficiary?*

   _____ Yes **[If yes, go to question 3]**

   _____ No **[If no, thank respondent for their time and end call.]**

3. *Do you currently (or have you ever) work(ed) for a home health service, are you a working or retired doctor or nurse, or are you a current or retired employee of a Federal Government Health Agency?*

   _____ Yes **[If yes, thank respondent for their time and end call.]**

   _____ No [**If no, go to question 4.]**

4. *What is your race or ethnicity?* **[Do not read answers.]**

   _____ African American (not of Hispanic descent)
   _____ White Non-Hispanic
   _____ Hispanic

_____ Native American/American Indian
_____ Asian or Asian American
_____ Other (please specify _____

5. *What was the last grade you completed? [Seek a range]*

____ 3rd grade or less **[thank respondent and end call]**
____ 4th-8th grade
____ 9th –12th grade, High School Diploma or GED, Technical or Trade School
____ Some College
____ College Graduate, Graduate School **[thank respondent and end call]**

6. *Have you [or the person you care for] received any home health care services in the past three years?* **[Examples, if needed, include: durable medical equipment, skilled nursing care, and homemaking services.]**

_____ Yes **[Go to Invitation]**
_____ No **[Go to Invitation]**

Invitation:

Thank you for answering my questions. You are eligible to participate in the individual interview about medical care information. It will last about one and a half to [two] hours and you will be paid $50 for your time. Your experience and opinions are very important to us. During the discussion we will be speaking in English and reading some print materials, so it is very important that you are comfortable speaking and reading English.

Are you comfortable speaking and reading English?

❑ ***Yes***

❑ ***No*** *[Thank respondent and end call.]*

The interview will be held on _____ at _____.

Can you attend?

_____ ***Yes***
_____ No **[Thank respondent for their time and end call.]**

Could I please have your address so that we can send you a confirmation letter and a map?

_____

_____

If you need glasses for reading, please bring them with you for your interview.

Thank you.

APPENDIX VI: COGNITIVE INTERVIEW PROTOCOL[7]

[7] This is the final version of the interview protocol, which reflects the edits made in response to respondent feedback from previous rounds of interviews. This was also edited and reviewed by CMS and UCHSC.

COGNITIVE INTERVIEW PROTOCOL[8]

Dates: March 25-26, 2002
Location: Tampa, FL
Project: Consumer Testing Regarding Public Dissemination of Home Health Care Quality Data Based on OASIS Outcome Reports

Introduction

Thank you for coming today. My name is ____, and I work for a private company that is doing some research for the federal agency that runs Medicare. We're interviewing people in the Tampa area to get their thoughts about information Medicare might want to give people about home health care services.

We will be recording our discussion today, for research purposes, but whatever you have to say will be strictly confidential.

We expect to be finished in about an hour and a half.

Do you have any questions before we start?

Warm-Up (no more than 15 minutes)

- When I say, "home health care," what is the first thing that comes to your mind?

- What types of services do home health care agencies provide? Why are these important?

- Have you had any experience with home health care – either for yourself, or for someone you've helped take care of?

    - What kinds of services did you receive? What did people do for you? What was that experience like?

- How would you know whether a home health agency was doing a good job? [*Clarify if necessary:* When we use the term "home health services," we're talking about any sorts of professional health services that people may get in their own home, rather than in a hospital, clinic, or doctor's office. This may include professional nursing care or visits by

[8] This is the final version of the interview protocol, which reflects the edits made in response to respondent feedback from previous rounds of interviews. This was also edited and reviewed by CMS and UCHSC.

home health aides or special treatments that may be given to people in their homes (such as physical therapy and speech therapy). The goal of home health care is to help people remain independent in their own homes, rather than having to go to a hospital or a nursing home.]

Home health scenario

Thank you for telling me about your experience and your opinions about home health care agencies. Now I am going to tell you about the story of an imaginary person that needs home health services. You may have read through this story in the waiting room before our interview. This is not a true story, but it is similar to the experience that many people have.

Do you have any questions before I read you the story?

Female Medicare Beneficiary Living with Husband

Mary is 72 years old and lives with her husband, John. She had a stroke recently and she is about to be released from the hospital. Mary's stroke has made it difficult for her to do everyday activities on her own and she will have trouble living at home without help until she is fully recovered. She needs help with household chores, help with getting to the bathroom, and help with meeting her daily needs such as feeding herself and personal care. She also has some trouble speaking and has become confused and disoriented in the past couple of days and may need some help with her speech. Mary has been told by the hospital that she will need to receive health care in her home for a period of time. As Mary's husband, what types of things would you want to know about a home health care agency so that you could help her choose the best one?

Male Medicare Beneficiary Living with Wife

Jack is 72 years old and lives with his wife, Emily. He had a stroke recently, and is about to be released from the hospital. Jack's stroke has made it difficult for him to do everyday activities on his own and he will have trouble living at home without help until he is fully recovered. He needs help with getting to the bathroom and fixing meals, help with meeting his daily needs such as getting dressed and bathing himself. He also has some trouble speaking and has become confused and disoriented in the past couple of days and may need some help with his speech. Jack has been told by the hospital that he will need to receive health care in his home for a period of time. As Jack's wife, what types of things would you want to know about a home health care agency so that you could help him choose the best one?

Caregiver

Your 73 year-old Uncle named Jack had a stroke recently, and is about to be released from the hospital. Your Uncle Jack's stroke has made it difficult to do everyday activities on his own and he will have trouble living at home without help until he is fully recovered. He needs help with getting to the bathroom and fixing meals, meeting his daily needs such as getting dressed and bathing himself. He also has some trouble speaking and has become confused and disoriented in

the past couple of days and may need some help with his speech. Jack has been told by the hospital that he will need to receive health care in his home for a period of time. As Jack's caregiver, what types of things would you want to know about a home health care agency so that you could help him choose the best one?

For the rest of the interview, I want you to pretend that you are Mary (or Jack's) friend or caregiver. Think about what advice you would give him or her about choosing a home health agency.

Review of Categories (20 minutes)

Medicare wants to give people information about home health services to help them choose the best home health agency for their needs, or their family member's needs.

When people are looking for a home health agency, they may look at all sorts of information, including how much it costs, what sorts of services it offers, and so forth. For today, we'll focus on another type of information people may also want to take into account when they are looking for home health services.

I'm going to show you some information about eight general categories that you may (or may not) want to take into account when you're looking for home health services. Please look these over, take some time to read them. And tell me what's going through your mind, as you look these over. Think out loud for me.

> **[Give respondent all nine cards or pages with the category definitions and explanations in plain language. Let respondents look them over, however they want. Encourage them to think out loud as they peruse them, before launching into specific queries, below. Record the categories reviewed on the spreadsheet provided.]**

- Tell me what each of these categories means to you. *[Ask for some response about each, but don't dwell on the ones they show no interest in.]*
- Which of these would be most important to you? *[Ask them to pick one or two of the most important ones.]*
- Why is this important? Why is it more important to you than some of the other categories?
- Are there any categories that don't interest you very much at all?

Review of Items (20 minutes)

[Select cards or pages with items, representing the one or two categories they chose. Show respondent one category at a time.]

Now, I'd like you take a closer look at some of the things that might make up the category(ies) you chose. They represent measures that might be reported to show you how well a home health agency was doing its job. Take some time to look over these items – and, once again, think out loud for me.

- What do these items mean to you? *[Again -- ask for some response about each, but don't dwell on the ones they show no interest in.]*

- Which of these are most important to you?

- Which of these do you think best represent the overall category of ____?

    - Tell me if there were any surprises here?

[Repeat for second category, if they chose two.]

[With the time remaining, ask them to look at least briefly at one of the categories they did NOT choose.]

Now, I'd like to ask you to take a look at some items in one of the categories you did not choose.

- Are there any of these items that you think would be important to know about?

- Which ones would be most important?

Thank you and good-bye.

APPENDIX VII: RESPONDENT CHARACTERISTICS

PHASE I RESPONDENT CHARACTERISTICS

No.	Sex	Age	Beneficiary/ Caregiver Status	Ethnicity	Education Level	Home Health Experience	Location
1	F	65-74	Caregiver	Caucasian	Some College	Yes	Tampa, FL
2	M	75+	Beneficiary	Caucasian	High School	Yes	Tampa, FL
3	M	75+	Beneficiary	Caucasian	High School	Yes	Tampa, FL
4	M	65-74	Beneficiary	Caucasian	High School	Yes	Tampa, FL
5	F	65-74	Beneficiary	Caucasian	High School	No	Tampa, FL
6	F	75+	Beneficiary	African-American	High School	Yes	Tampa, FL
7	F	Under 65	Caregiver	Hispanic	Some College	Yes	Tampa, FL
8	F	Under 65	Caregiver	African-American	Some College	No	Tampa, FL
9	M	75+	Beneficiary	Caucasian	Some College	No	Tampa, FL
10	M	65-74	Beneficiary	Caucasian	Some College	No	Tampa, FL
11	F	Under 65	Caregiver	Caucasian	High School	No	Tampa, FL
12	F	75+	Beneficiary	Hispanic	Some College	No	Tampa, FL
13	F	65-74	Beneficiary	Caucasian	High School	No	Tampa, FL
14	F	65-74	Beneficiary	Caucasian	Some College	No	Tampa, FL
15	F	75+	Beneficiary	Caucasian	Some College	No	Baltimore, MD
16	M	Under 65	Caregiver	Caucasian	High School	No	Baltimore, MD
17	M	Under 65	Caregiver	Caucasian	High School	Yes	Baltimore, MD
18	F	65-74	Beneficiary	African-American	High School	Yes	Baltimore, MD
19	M	65-74	Beneficiary	Caucasian	High School	Yes	Baltimore, MD
20	F	Under 65	Caregiver	African-American	Some College	Yes	Baltimore, MD

No.	Sex	Age	Beneficiary/ Caregiver Status	Ethnicity	Education Level	Home Health xperienc e	Location
21	F	Under 65	Caregiver	Caucasian	Some College	Yes	Baltimore, MD
22	M	65-74	Beneficiary	Caucasian	High School	Yes	Baltimore, MD
23	M	65-74	Beneficiary	Caucasian	Some College	No	Baltimore, MD
24	F	65-74	Caregiver	African-American	High School	Yes	Baltimore, MD
25	F	65-74	Beneficiary	African-American	Some College	No	Baltimore, MD
26	M	65-74	Beneficiary	Caucasian	High School	Yes	Baltimore, MD
27	M	65-74	Beneficiary	Caucasian	High School	Yes	Baltimore, MD
28	F	75+	Beneficiary	Caucasian	Some College	No	Baltimore, MD
29	F	75+	Beneficiary	Caucasian	High School	No	Baltimore, MD
30	F	65-74	Caregiver	African-American	Some College	Yes	Baltimore, MD
31	M	Under 65	Beneficiary	African-American	High School	Yes	Baltimore, MD