BearingPoint

Formerly KPMG Consulting

CONSUMER TESTING OF THE HOME HEALTH COMPARE WEBSITE PROTOTYPE

FINAL REPORT

CMS Contract # 500-01-0002
Task Order #10, Subtask #1:
Website Consumer Usability Testing
and Display Development for Home Health Compare

Submitted to:
Rosemary Lee
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Prepared by:
BearingPoint
1676 International Drive
McLean, VA 22102-4828

Under Subcontract to:
Ketchum Public Relations
2000 L Street, NW #300
Washington, DC 20036

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EXECUTIVE SUMMARY

Background

The Centers for Medicare and Medicaid Services (CMS) intends to launch a website entitled "Home Health Compare" on www.medicare.gov in April of 2003. This will mark the beginning of Phase I of the Home Health Quality Initiative which will involve eight states: Florida, Massachusetts, Missouri, New Mexico, Oregon, South Carolina, West Virginia, and Wisconsin. For these Phase I states, the Home Health Compare Website will display 11 quality measures from the Outcome and Assessment Information Set (OASIS) as well as some administrative information about home health agencies. Information about home health agencies in the remaining 42 states, Washington, D.C. and two territories will be added to the website in the fall of 2003.

The Centers for Medicare and Medicaid Services (CMS) contracted with Ketchum Public Relations and its subcontractor BearingPoint to develop a prototype for Home Health Compare, using specifications provided by CMS, and to conduct usability testing of this prototype with consumers. The findings from the consumer testing of the prototype will be utilized by CMS and American Management Systems, Inc. (AMS), the www.medicare.gov website development contractor, as they construct the Home Health Compare website.

Methodology

The research team worked in collaboration with CMS to design the prototype Home Health Compare website using narrative language developed by CMS, and a format and structure based on that of Dialysis Facility Compare. CMS also provided specifications that described the prototype's functionality.

The prototype was tested with the two primary audiences, informal caregivers and home health care professionals, in three markets, Baltimore, MD, Ft. Lauderdale, FL and Waltham, MA. Informal caregivers are defined as a family member or friend of a Medicare beneficiary who provides unpaid services on a regular basis, such as assisting the beneficiary in carrying out activities of daily living and/or making health care decisions when the beneficiary is unwilling or unable to do so on their own. They are to be distinguished from paid companions or housekeepers. They will also be referred to as "caregivers" throughout this report.

Caregivers were interviewed in dyads (n=37) and professionals were interviewed in small focus groups of four (n=24). Each participant was given their own computer during testing so they could explore the information at their own pace.

Key Findings

Both caregivers and health professionals responded positively to the website prototype overall, although their understanding of its contents varied greatly.

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Caregivers' Responses to the "Home Health Compare" Website Prototype

♦ Informal caregivers responded favorably to web-based Medicare information on home health care and reported that they would be likely to use it.

♦ Caregivers have difficulty understanding and using the website as intended without assistance, even though respondents reported being comfortable with computers and the internet when they were recruited.

♦ The information needs of caregivers and their expectations of the website are shaped by their current circumstances.

♦ Caregivers do not perceive a choice when selecting a home health agency.

♦ Caregivers liked that the Home Health Compare website provided a lot of information, but they also report being overwhelmed by it.

♦ Participants liked the "Agency Characteristics" tables, which provide a brief profile of home health agencies in a particular market.

♦ Caregivers report some problems interpreting data displays and find using the data to select the "best" home health agency difficult.

♦ Most difficulties with understanding and using the website relate to concepts, not language.

♦ Computer-savvy respondents got the most out of the website. Users who skimmed the website content and those with few computer skills were more likely to get frustrated and abandon the effort.

♦ Reviewing Home Health Compare website seen as good first step in selecting a home health agency, but not enough to make a final decision.

♦ There were no distinct differences between caregiver respondents who reported home health care experience and those who did not. "Inexperienced" caregivers often knew about the home health care experiences of other family members and friends, and "experienced" caregivers often did not distinguish between their experiences with Medicaid (custodial and long-term care) and Medicare (short-term rehabilitative services).

Caregivers' Responses to Quality Measures

♦ Caregivers expressed the most interest in measures that were related to their (the caregivers') current needs and concerns, which were the 'activities of daily living.'

♦ Some measures are seen as being redundant.

Caregivers' Problems Understanding and Using Quality Measures

♦ While caregivers could understand the meaning of the quality measures, they had difficulty using them as indicators of agency performance.

♦ Most caregivers had difficulty understanding the concept of improvement as it relates to home health care.

♦ Caregivers commonly misinterpret a number of the quality measures.

Provider Responses to the "Home Health Compare" Website Prototype

♦ Overall, discharge planners and home health nurses understand the Home Health Compare website content and function and see it as a useful tool in their work with families.

♦ Home health nurses, especially, think that public reporting of quality measures will foster quality improvement.

♦ Hospital discharge planners are receptive to the website and likely to use it to explain Medicare home health options to families.

♦ Some professionals raised concerns about consumers' ability to use and interpret the information without assistance.

♦ Home health care professionals' response to public release of quality measures varied by site.

Providers' Responses to Quality Measures

♦ Providers have questions about data validity and reliability.

♦ Some professionals had concerns about usefulness or relevance of quality measures to consumers.

♦ Providers recognize measures as desired outcomes of home health care and are most attracted to the measures associated with clinical and adverse outcomes.

BACKGROUND

The Quality Initiative, announced in November 2001, represents the commitment of the Department of Health and Human Services and the Centers for Medicare and Medicaid Services to assure quality health care for all Americans through accountability and public disclosure. The aim of the initiative is (a) to empower consumers with quality of care information to make more informed decisions about their health care, and (b) to stimulate and support providers and clinicians to improve the quality of health care.[1] In November 2002 the Quality Initiative was launched nationally for nursing homes (the Nursing Home Quality Initiative), and will be expanded to the nation's home health agencies (the Home Health Quality Initiative) and hospitals in 2003.

Phase I of the Home Health Quality Initiative is expected to begin in April of 2003 with the display of quality information for the home health care agencies in eight pilot states: Florida, Massachusetts, Missouri, New Mexico, Oregon, South Carolina, West Virginia, and Wisconsin on Medicare's website for consumers, on www.Medicare.gov. This information will be made available to the public on a new web page entitled "Home Health Compare." Here, consumers will be able to find information about all Medicare certified home health agencies in the eight pilot states. The website will also allow users to see how each of these agencies rates on 11 quality measures based on the Outcome and Assessment Information Set (OASIS), which will allow for the comparison of performance across agencies. Administrative data for all Medicare certified home health agencies will also be available. CMS plans to publicly release this quality information for home health agencies in the remaining 42 states, the District of Columbia, and two territories in the fall of 2003.

CMS contracted with Ketchum Public Relations and its subcontractor BearingPoint to develop a prototype for Home Health Compare using specifications provided by CMS, and to conduct usability testing of this prototype with consumers. This research will be used to advise the development of the Home Health Compare website being developed for www.medicare.gov by AMS.

This research builds upon previous work performed by the Ketchum team in the first half of 2002. At that time, researchers from BearingPoint collaborated with colleagues from CMS and the University of Colorado Center for Health Services Research to test plain language versions of 54 OASIS measures with consumers as well as with physicians and hospital discharge planners.[2] The project team presented findings from this research to a Technical Expert Panel convened in October 2002 by the Agency for Healthcare Quality and Research (AHRQ) to aid both CMS and AHRQ in their selection of quality measures for public reporting. CMS subsequently selected 11 OASIS-based quality measures to be displayed on Home Health Compare.

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[1] Overview of the Home Health Quality Initiative. Accessed on March 13, 2003 at http://www.cms.hhs.gov/quality/hhqi/.
[2] "Results of Testing OASIS Measures with Doctors and Discharge Planners: Final Report", BearingPoint under contract to Ketchum Public Relations, October 1, 2002.

METHODOLOGY

Research Goals and Objectives

The purpose of this project was to develop a prototype Home Health Compare website and to test the prototype with informal caregivers of Medicare beneficiaries and with health care professionals

Specific research questions included the following:

- Do respondents understand the content of the website, including "plain language" narrative text, tabular information on home health agency characteristics, and graphic displays of quality measures?

- Do the respondents understand how quality measures relate to home health agency performance and quality? Do they interpret the measures, as displayed, as comparative indicators of agency performance?

- Can respondents use the information on the website, as intended, to identify home health agencies in given geographic areas and compare their characterstics and performance?

- Do respondents perceive the information on the website to be salient to the decision making process around home health care?

Prototype Website Development

The research team worked in collaboration with CMS to design this prototype, using "plain language" narrative text developed by CMS, a format and structure based on that of the existing "Dialysis Facility Compare" website on www.medicare.gov, and detailed specifications provided by CMS. The testing prototype used real OASIS data submitted by CMS. However, the names and addresses of the home health agencies were obscured. While the prototype displayed the same links to sites outside this web page as those on Dialysis Facility Compare, to limit confusion during testing, these links were not live.

The Ketchum team drew on prior website testing experience to develop a prototype website that was as user-friendly as possible. The prototype was also developed in compliance with Section 508.

Site Selection

The research team conducted consumer testing of the Home Health Compare prototype in three settings: Baltimore, MD, Fort Lauderdale, FL and Waltham, MA. Baltimore was selected as the first of the three sites so that members of the CMS team could observe testing. The other two sites were selected in collaboration with the CMS project officer for the following reasons: The states in which they are located will be involved in Phase I of the Home Health Quality Initiative; the locations have a large number of home health agencies in the vicinity and high home health utilization rates; and they represented some degree of geographic variation and racial and ethnic diversity.

Participant Recruitment

The groups selected for recruitment reflected target audiences identified for home health information during prior OASIS research. These audiences include informal caregivers of Medicare beneficiaries and health care professionals who refer patients to home care or directly provide home care (specifically, hospital-based discharge planners and home health nurses, therapists and social workers). Here, the term "informal caregiver" is used to refer to a family member or friend of a Medicare beneficiary who assists the beneficiary in carrying out activities of daily living and/or making health care decisions when beneficiaries are unwilling or unable to do so on their own.

Due to the nature of the recruitment criteria for this protocol, the quick turnaround time required by CMS, and the technical needs of this project, the project team chose to use professional testing facilities (rather than community-based organizations) for recruitment and as testing sites.

The following types of participants were recruited and tested:

- Informal caregivers with past experience with home health care for their loved ones: three groups of two per site (N=18)

- Informal caregivers without past experience with a home health agency: three groups of two per site, plus one floater (N=19).

- Hospital discharge planners, including nurses and medical social workers: one group of four per site (N=12).

- Home Health nurses, social workers and therapists: one group of four per site (N=12).

To be eligible to participate, caregivers needed to provide at least 14 hours per week of assistance to the Medicare beneficiairy. This assistance included both indirect care such as preparing meals, doing household chores taking the person to the doctor, and helping with health care decisions as well as more direct physical care such as bathing and feeding. Caregivers were also required to be comfortable using the Internet to search for information. A mix of ages was recruited, so that caregivers representing both the 40-65 and 66-75 age range were represented.

Caregivers were also recruited to fall into two groups: those whose loved one had experienced home health care within the last year and those who had no past experience with home health but anticipate the need for such at some time in the near future. This strategy was designed to reveal how prior experience (or its absence) affected caregivers' responses to the website. Caregivers received $50 each for their participation in these interviews.

It must be noted however, that these two caregivers groups turned out to be less distinct than had been anticipated. A number of those in the "Not Experienced" group did have some prior experience with home health through another friend or family member other than the person they currently cared for. Also, some of those in the "Experienced" group had only received the type of home health care that Medicare does not cover, such as Medicaid-subsidized custodial and long-term care.

A focus group was held with hospital-based discharge planners in each of the three testing locations. These professionals were recruited from at least three different hospitals, were required to have worked as a discharge planner for at least three years and to have referred at least 10 patients to home health care agencies in the past 6 months. They were excluded if they worked primarily with Ob-Gyn or Pediatric patients or referred primarily to a home health care agency affiliated with the hospital at which they were employed. Discharge planners received between $75-$100 each for their participation, depending on the site.

Another focus group was held in each location with a mix of home health care professionals including skilled nurses, occupational or physical therapists and licensed social workers working. Professionals representing a mix of agencies and providing a range of services were recruited to participate. Participants in this group were also required to have worked in home health care for a minimum of three years. Nurses, therapists and social workers providing primarily behavioral, psychiatric or psychological services were excluded from participation because OASIS measures featured on the website were related to physical, rather than mental, health status. Home health care professionals received between $75-$100 each for their participation, depending on the site.

Further information about participant characteristics in provided in Appendix I.

Usability Testing

Based on prior experience with informal caregivers and after consultation with project officers, the research team decided to use dyads rather than focus groups for testing with informal caregivers, that is testing two participants simultaneously. This allowed the participants to react to each other's ideas and opinions and assist each other with navigation and interpretation of the website. Testing in groups of two also allowed the research team to test the site with a larger number of people in a relatively short amount of time. The protocol for interviews with caregivers are attached in Appendix II.

Health care professionals were tested in small focus groups of four people. Each participant (both caregivers and professionals) had their own computer for testing, allowing them to interface with the website independently as well as review parts of the site as a group. The protocols for focus groups with health care professionals are attached in Appendix II.

KEY FINDINGS

This section describes how informal caregivers and health care professionals responded to the "Home Health Compare" Website Prototype.

Caregivers' Responses to the "Home Health Compare" Website Prototype

♦ **Caregivers responded favorably to the idea of a Home Health Compare website and reported that they would be likely to use it.** Almost every caregiver interviewed liked the idea of Medicare establishing a public website with comparative information about home health agencies. People made comments such as, "*This is a world of knowledge that is permanent and available,*" and "*It saves time in a busy world.*" Most caregivers said they would be likely to use this website to find more information if they were helping their loved one choose a home health agency. Caregivers were even more enthusiastic about using the website for situations when the person they would be helping lives in another state.

> "*This would be great if you were looking for a home health agency, you can look in your area.*"

> "*This would be a blessing if you had someone out of state.*"

♦ **Caregivers have difficulty understanding and using the website as intended without assistance.** Most caregivers did not fully grasp the purpose of the website or how to use it on their own. Many factors contributed to this including: not understanding that Medicare covers only certain types of home health care, a general lack of understanding about quality measures, a lack of perceived choice when selecting home health agencies, problems with navigation (both due to lack of skill on the part of the user and cumbersome elements of the website), and an overwhelming amount of information presented on the site.

♦ **The information needs of caregivers and their expectations of the website are shaped by their current circumstances.** Caregivers without home health experience did not distinguish between Medicare covered and non-Medicare covered services and did not recognize that Medicare covers only post-acute rehabilitation, not long-term and custodial home care. Many caregivers were looking for assistance with custodial care, and they often became frustrated with the website because it did not help them find the services they wanted and needed most. A number of caregivers expressed a desire for information about other types home health care to be included in the site, such as Medicaid and private-pay options.

♦ **Caregivers do not perceive a choice when selecting a home health agency.** This finding was especially apparent for caregivers who had some experience with home health care in the past. This group most often reported that the home health agency they used was selected for them by the hospital's discharge planner or that they went with whatever the doctor recommended. These caregivers were less likely to feel a website like this one is necessary or to report being likely to use it.

♦ **Many reported liking the large amount of detailed information on the website, but many were overwhelmed by it.** Users often stated that they liked having one website with so much information about home health. *"This is very informative. I like not having to go to a zillion different sources."* and *"There is a lot of information here. It requires a lot of concentration, but it is good…the more information the better."* However, many users also reported feeling overwhelmed by the amount of information to read and synthesize. *"This is overkill, more than what I would read."* *"Some of the explanations were long, three paragraphs is more than I want to read. When you read it, it is clear, but you might be able to cut it down, it is a bit repetitive."*

♦ **Participants liked the "Agency Characteristics" tables, which provide a brief profile of home health agencies in a particular market.** Caregivers particularly liked the information about the structural characteristics of home health agencies, such as services offered, date of accreditation, and non-profit vs. private status. They felt the "Agency Characteristics" tables were simple, clear and informative. Respondents were interested in seeing additional information in these tables, however, such as satisfaction rates, complaints and cited deficiencies as well as specialized services. There was strong interest in the checklist that they could use to find out more detailed information about each agency.

♦ **Caregivers report some problems interpreting data displays and find using the data to select the "best" home health agency difficult.** Most users were able to see that the bar graphs compare agency performance on a particular measure, and were able to discern which agency was performing the best for each graph. There were, however, many confusing elements to the bar graphs including "Not available" labels, zero and 100% scores, measures for which the larger percentages represent worse performance, and phase I and state rates. Users found it very difficult to compare information across graphs and found large differences between the performance of different agencies on one measure and the differences in performance for one agency across measures to be disconcerting and confusing. Because agencies often performed above average on some measures and below average on others, users had a hard time selecting one agency as the "best" and were more likely to use the information to rule out the agencies that seemed to perform poorly overall or to be otherwise suspect. Agencies were often considered suspect and ruled out because they had a "Not Available" label or a score of zero or 100% on one or more measures. Many users reported wanting to print out all of the tables so they could line them up and compare them and many requested one large table where they could view all of the information in one place.

> *"I didn't find this useful. It didn't answer a lot of the questions that I have, and what I did see here gave conflicting information. I wouldn't be able to make a decision based on that."*

> *"It is very confusing that the agency that was performing worse before is now much better. Why would that be?"*

♦ **Most difficulties with understanding and using the website relate to concepts, not language.** Confusion about the intended purpose of the website and how to interpret quality measures led to most of the difficulties caregivers had using the website. Users who expressed confusion and frustration during testing were instructed to read explanations and then probed to see if this was helpful. While

most participants reported that the language in the text was written simply and clearly, the explanations often did not ameliorate their confusion or aid them with interpreting and using the site.

♦ **Computer-savvy respondents got the most out of the website. "Skimmers" and those with few computer skills were more likely to get frustrated and abandon the effort.**
It was expected that those with prior experience with home health care would relate to the website differently than those without previous experience. However, two other distinct groups of users emerged during testing of the website: the computer-savvy vs. the non-computer-savvy and the readers vs. the skimmers. Those who were not computer-savvy had a hard time navigating and finding information but recognized that this was due to lack of skill on their part rather than problems with the website. This group was unlikely to be critical of the website design and less likely than those who were computer-savvy to be able to engage with and comment on the content of the site.

"Readers" were respondents who carefully reviewed all of the links on the home page before going on to look at the rest of the site. These type of respondents often missed the search tool all together, got lost in the website, and did not know how to proceed.

"Skimmers" scanned the pages quickly and went straight to the search tool or the next action without reading directions or background information. While this group usually found the quality information in a relatively short amount of time, they were often confused about what they were looking and how to interpret and use this information. This group was more likely to ask the research staff questions than to read through information and try to figure it out on their own. This group was impatient and would probably be likely to abandon a website that did not get them to information they could visually perceive as important within a few quick steps.

♦ **Reviewing "Home Health Compare" website was seen as good first step in selecting a home health agency, but not enough to make a final decision.** Most caregivers indicated that the website would be somewhat helpful for selecting a home health agency. At the very least, it could be used to rule out agencies. The majority of respondents, however, reported needing more information before making a final selection of a home health agency.

> *"This is a good initial step, but you will need to do more research to decide."*

> *"I wouldn't choose one based on this, but I might be able to rule one out. At least I can see what is available in a given area."*

Caregivers' Responses to Quality Measures

♦ **Caregivers perceived measures related to the 'activities of daily living' as most important because these measures are directly related to the caregivers' roles and responsibilities.** When asked to select which measures were most important to them, caregivers most often sited the measures related to bathing, getting dressed, taking medicines correctly, walking and moving around, and confusion. When probed as to why these measures are more important than others, caregivers reported that these measures refer to the tasks that are most burdensome to them as caretakers and represent the most basic needs of the person receiving home health care.

♦ **Some measures were seen as being redundant.** "Patients who get better at bathing" and "Patients who stay the same (don't get worse) at bathing," were seen as redundant. For this reason, "Patients who stay the same (don't get worse) at bathing" was most often selected as the least important measure. Most caregivers did not differentiate between the measures "Patients who had to be admitted to the hospital" and "Patients who need urgent, unplanned medical care," and many felt one of these could be eliminated. Also, "Patients who get better at walking or moving around," "Patients who get better at getting in and out of bed," and "Patients who get better getting to and from the toilet" were often seen as referring to general mobility skills and were therefore seen as similar if not duplicative. Users made comments such as *"If they can get in and out of bed they can get to and from the toilet" and "If they can get out of bed they can probably walk around."* While most people referred to the measure "Patients who have less pain when moving around" as the "pain" measure, some pointed out that this measure sounded a lot like "Patients who get better at walking or moving around" and wished there was a more general pain measure. *"What about people who have pain when they are sitting or lying down? Nothing here talks about that."*

Caregivers' Problems Understanding and Using Quality Measures

♦ **Caregivers had difficulty understanding Quality Measures as indicators of agency performance**. Caregivers were not familiar with the use of quality measures as tools for comparing home health agency performance. They often claimed that outcomes could be caused by many factors beyond the agencies control. For example, comments like this one were common.

> *"There are all kinds of reasons why that [being readmitted to the hospital] would happen, and it might not be the agency's fault."*

Caregivers thought of the quality measures as outcomes they would like for a loved one receiving home health care, but report that they would rather see information about satisfaction rates, complaints and citations than how an agency scores on these measures and would trust a personal referral more than this data when making an agency selection.

♦ **Most caregivers had difficulty understanding the concept of improvement as it relates to home health care.** Many of the caregivers interviewed took care of people in functional decline or those

with degenerative diseases such as dementia where improvement is unlikely. For this reason, they had difficulty understanding why most of the quality measures relate to improvement.

"She is not going to get any better, that is why I need help"

"What I don't like is 'patients who get better at…' I just need someone who will help her. They won't be able to help her get better. This is the problem with dementia."

♦ **Caregivers commonly misinterpret a number of the quality measures.** While the language used for the measures was simple and easy to understand, many caregivers still misinterpreted some of the quality measures. The measure "Patients who are confused less often" was often seen as referring to dementia and not to disorientation due to medication or illness. "Patients who get better getting too and from the toilet" was often interpreted as relating only to the mobility skills needed to walk to the toilet rather than the skills needed to use the toilet. This probably explains why this measure was not one of the measures selected as most important by caregivers who, in previous research emphasized incontinence as a major strain on them. Also, some caregivers interpreted the measures "Patients who had to be admitted to the hospital" and "Patients who need urgent, unplanned medical care" as referring to how well the agency responded to emergencies (rather than as adverse outcomes), and therefore interpreted higher scores as better. Testing revealed that most users did not read the explanations of the measures even when they reported not understanding the measure. Instead they tended to disregard measures they did not understand and not take them into consideration when comparing home health agencies.

Provider Responses to the "Home Health Compare" Website Prototype

♦ **Overall, discharge planners and home health nurses understood the Home Health Compare Website content and function and saw it as a useful tool in their work with families.** While many of the home health professionals had similar problems as the caregivers with navigation, for the most part they were better able to understand and use the website as intended. This is probably because they are more familiar with thinking about quality and at least the home health nurses and therapists recognize the measures as being derived from the OASIS forms they complete. *"This is OASIS. We're always hoping that people will use these things."* Most thought the website was a good idea and reported that they would be likely to use it in their work, or at least check it to see if it was in line with their knowledge about the performance of agencies in their area.

♦ **Home health nurses, especially, thought that public reporting of quality measures would foster quality improvement.** This finding was particularly true in competitive markets. Nurses made comments such as *"It is about time agencies competed on the basis of quality"* and *"This will put a lot of pressure on agencies to improve."* However, it should be noted that in Baltimore, where there is a shortage of nurses and home health agencies, the quality measures were almost completely disregarded and considered useless.

♦ **Hospital discharge planners were receptive to the website and likely to use it to explain Medicare home health options to families.** Discharge planners reported that they would be especially likely to use the website when making out of state referrals, and some said they would use the tool for their regular referrals in conjunction with other information they have. Many discharge planners were enthusiastic about using the website for patient/caregiver education and said they would print out some of the information such as "What is home health care" and "What does Medicare cover" and give this to their patients. *"This provides a lot of information that patients ask for all the time."* Discharge planners also said the website would be helpful in facilitating the understanding of choice with their patients, *"Families would be interested in this. They don't realize they have a choice."*

> *"People ask for our opinion, but it is better if we can give them the tools to make the comparisons themselves."*

♦ **Some professionals raised concerns about consumers' ability to use and interpret the information without assistance.** The professionals were aware of how confusing and overwhelming information about home health care and Medicare can be for patients. Most felt that the language was very simple and easy to understand, but worried that most patients would not be able to use the website on their own and would need considerable assistance from family members or from their nurses and discharge planners.

♦ **Home health care professionals' response to public release of quality measures varied by site.** In locations where there was some competition between home health agencies, and enough agencies to meet demand (Ft. Lauderdale, FL and Waltham, MA), the release of the website and the quality measures was perceived as a beneficial effort that could only improve quality. However, in Baltimore, where there is a serious nursing shortage and nurses reported that home health agencies were turning patients away because they were overloaded, the release of these measures was viewed as being useless and possibly even detrimental.

Providers' Responses to Quality Measures

♦ **Providers had questions about data validity and reliability.** Home health nurses who had past experience collecting OASIS data frequently had questions about the validity of the data. Many also had questions about case-mix adjustment. This was especially true in Baltimore where nurses felt that some home health agencies were "cherry-picking" patients.

> *"Every home health nurse fills out those forms in a different way,"*

> *"How an agency scores will depend on who they have on staff at any given moment. How often will this information be updated?"*

♦ **Some professionals had concerns about usefulness or relevance of quality measures to consumers.** Participating home health professionals acknowledged that this information was interesting and useful, but some pointed out that this was not the type of information that most patients and caregivers seek when they are selecting a home health agency. The home health professionals described the kinds of questions they hear from their patients and suggested many items to include in the checklist for persons selecting a home health agency. (See Appendix VI for a complete list of questions recommended for the checklist).

> *"What people really want is for someone to show up and not be late. That is more important than what their percentage is."*

> *"People really want to know word of mouth so they can choose which is best- they want customer satisfaction. Our agency sends out surveys after the service, it would be nice to include this info."*

♦ **Providers recognized measures as desired outcomes of home health care and were most attracted to the measures associated with clinical and adverse outcomes.** When asked which measures were important to them, the professionals most often sited "Patients who get better at taking their medicines correctly," "Patients who need urgent, unplanned medical care," "Patients who need to be admitted to the hospital," "Patients who get better at walking or moving around," and "Patients who have less pain when moving around." When probed for why they selected these measures, they explained that these measures refer to more serious issues and that these are the measures that are more likely to have an effect on other measures.

> *"Sure it is nice to get a bath, and that is what the patient might think is most important, but you won't die if you don't get a bath in a few days." " If you are taking your medicines correctly that will help with other things like pain and confusion."*

RECOMMENDATIONS

The findings from this qualitative research, while not generalizeable, did generate a number of ideas about how to improve the Home Health Compare website, issues to address in the Home Health Initiative Phase I Communications Plan, and questions to explore in future research.

How to improve the website

♦ **Call attention to the scope and purpose of the home health care information on the home page.** As discussed above, many caregivers expected the website to provide them with information about long-term care for a dependent elder and custodial services not covered by Medicare. As a result, they often became confused and frustrated when they could not find information on this website. There are at least two potential remedies for this issue: (1) the website could provide links to such information, or (2) the home page could manage the users' expectations by emphasizing that the website refers to post acute care for short-term rehabilitation, not to long-term or custodial care.

♦ **Re-design the website to guide users in a linear fashion through all of the website content.** Many users did not get to the section of the site where home health agencies are compared on quality measures because they got lost, forgot their selections, looked up a definition and failed to return to the selection task, or chose another path. We recommend numbering the steps in the search tool as is done on "Nursing Home Compare." Also, we suggest making the option to view Quality Measures more prominent after the user views the agency characteristic tables. Another possibility would be to add a help feature to the home page for users with limited web experience, such as a "call-out box" that states, "New to the Web? Click here first for guidance."

♦ **Make other simple changes to improve navigability.** Testing revealed a number of stumbling blocks users face when navigating the Home Health Compare website. A number of small, simple changes could potentially reduce these problems greatly. For example, many users would select the state they wanted to search in the "Select a Geographical Area" box and then wait, rather than press the "Next Step" button.

♦ **Create comparison tables that are easier to read and use.** Many users expressed the wish to view all of the information about the agencies they selected in one table they could print out. While there are clearly feasibility problems with this request, it may be possible to create tables that compare all of the quality measures for one agency or other simplified amounts of information comparisons in a tabular format that a user could print out and compare.

> *"I want to look at a big chart so that I could compare all of the agencies, it is hard to do this here because you have to scroll up and down."*

♦ **Expand the agency characteristics tables to include more information.** Most of the people interviewed liked the agency characteristics tables and thought they were easy to read and understand. However, they wanted to see more information included in the tables that would help them compare agencies. For example, suggestions were made to add information about official complaints, and

about more specific types of services each agency provides, including what the agencies specialties are. Users also requested that the Home Health Compare website include links to the websites of the home health agencies when possible.

> *"It would be nice if there was a profile of the agency, their specialties, the size of the agency, etc. on top of just the services they cover."*

A more detailed list of specific recommendations for the website is provided in Appendix V.

♦ **Revise the explanations of quality measures to more clearly link them to agency performance.** When caregivers expressed confusion about the quality measures, the confusion most often arose because it was not clear how these outcomes were affected by home health care. When users did go to the explanation for a measure, they were often frustrated because they had to read through information that seemed obvious to find the information they were looking for. Many would read the first couple of sentences and give up. Our recommendation is to re-order and re-word the explanations for the quality measures so that the first paragraph contains the information about what a home health agency can do to improve a patient's outcome in this area.

Implications for the Home Health Quality Phase I Communication Plan

♦ **Explain to users the connection between the website and the CMS Quality Initiative.** People with Medicare and their caregivers are generally not familiar with using quality measures to compare performance. This general lack of understanding of what quality measures are, and how to use them, at least in part leads to difficulties with using the website as it is intended. It is our recommendation that the user is presented with some background information on the Home Health Compare home page about the CMS Quality Initiative and the Home Health Quality Measures as well as some directions about how these measures can be used to compare home health agencies.

♦ **Educate consumers about the meaning and uses of quality measures.** A broader education campaign around quality comparisons for health related decisions would be beneficial. If consumers are more aware of why quality measures are important and how they can be used to select health care services, they are more likely to seek out the information contained in this website and be able to use it effectively when making decisions about care.

♦ **Disseminate information about Home Health Compare to hospital discharge planners.** Discharge planners reported that they would be likely to use the Home Health Compare website in their work with families, and would probably also refer families to look at the website on their own. For these reasons, discharge planners are an excellent target audience for an information campaign around Home Health Compare.

♦ **Educate physicians about home health quality and choice.** Caregivers report that they are likely to choose whichever home health agency their doctor recommends. Discharge planners point out that

doctors rarely seem to make these selections based on quality information or educate their patients about home health care.

> *"There needs to be more information at doctors' offices and at the hospital. [Home health care] shouldn't be such a mystery. Dissatisfaction comes from false expectations."*

♦ **Establish ways to connect consumers to information about home health services not covered by Medicare.**   As explained previously in this report, many caregivers want information about respite, custodial, and long-term care, services which are not covered by Medicare. We believe it would increase the usefulness and credibility of the Home Health Compare website if these needs are acknowledged and links are provided to websites that provide information about these types of home health care. Ideally, there would be a centralized information source, or clearinghouse, that would integrate information on all types of home health services and coverage options and would make this available to consumers through various communications channels, such as a booklet, website, or toll free hotline.

Areas for further research

Finally, this research also generate a number of ideas to explore in future research.

♦ Are there better ways to display and disseminate the home health quality information?
♦ What effects do the materials on the Home Health Compare website have on consumers' knowledge, attitudes, and behaviors regarding home health agencies?
♦ Does the publicly reported information change the referral patterns of hospital discharge planners?
♦ What effects does the HHQI have on the home health industry? Was there an increase in quality improvement activities after the public release of OASIS measures?

♦

APPENDIX I: Participant Characteristics

Caregivers

Interviewee #	Dyad #	City	Group	Age Group
1	1	Baltimore	Experienced	40-65
2	1	Baltimore	Experienced	40-65
3	2	Baltimore	Experienced	40-65
4	2	Baltimore	Experienced	66-85
5	3	Baltimore	Experienced	40-65
6	3	Baltimore	Experienced	66-85
7	4	Baltimore	Not Experienced	40-65
8	4	Baltimore	Not Experienced	66-85
9	5	Baltimore	Not Experienced	66-85
10	5	Baltimore	Not Experienced	40-65
11	6	Baltimore	Not Experienced	66-85
12	6	Baltimore	Not Experienced	66-85
13	7	Ft. Lauderdale	Not Experienced	40-65
14	7	Ft. Lauderdale	Not Experienced	66-85
15	8	Ft. Lauderdale	Experienced	66-85
16	8	Ft. Lauderdale	Experienced	66-85
17	9	Ft. Lauderdale	Experienced	66-85
18	9	Ft. Lauderdale	Experienced	40-65
19	10	Ft. Lauderdale	Experienced	40-65
20	10	Ft. Lauderdale	Experienced	40-65
21	11	Ft. Lauderdale	Not Experienced	66-85
22	11	Ft. Lauderdale	Not Experienced	40-65
23	12	Ft. Lauderdale	Not Experienced	40-65
24	12	Ft. Lauderdale	Not Experienced	66-85
25	13	Waltham	Experienced	40-65
26	13	Waltham	Experienced	40-65
27	14	Waltham	Experienced	40-65
28	14	Waltham	Experienced	40-65
29	15	Waltham	Not Experienced	40-65
30	15	Waltham	Not Experienced	40-65
31	16	Waltham	Not Experienced	40-65
32	16	Waltham	Not Experienced	40-65
33	17	Waltham	Experienced	40-65
34	17	Waltham	Experienced	40-65
35	18	Waltham	Not Experienced	40-65
36	18	Waltham	Not Experienced	40-65
37	19	Waltham	Not Experienced	40-65

Hospital Discharge Planners

Interviewee #	Group #	City	Hospital	Specialty
1	1	Baltimore	Union Memorial	Internal, Orthopedics
2	1	Baltimore	Levindale Chronic Care	Internal Medicine
3	1	Baltimore	Union Memorial	Renal
4	1	Baltimore	Mercy Medical Ctr.	Orthopedics
5	1	Baltimore	University of Maryland	General Surgery
6	2	Ft. Lauderdale	North Ridge Med. Ctr.	Cardiac
7	2	Ft. Lauderdale	Health South	Orthopedics
8	2	Ft. Lauderdale	North Ridge Med. Ctr.	Orthopedics
9	2	Ft. Lauderdale	Hollywood Med. Ctr.	Med Surg./Cardiology
10	2	Ft. Lauderdale	Coral Springs Med. Ctr.	All Departments
11	3	Waltham	Faulkner Hospital	Internal/Orthopedics
12	3	Waltham	Quincy Med. Ctr.	All Departments
13	3	Waltham	Boston Medical Ctr.	Internal Medicine
14	3	Waltham	Mass General Hospital	Oncology/Gyn.
15	3	Waltham	Boston Medical Ctr.	Internal Medicine

Home Health Care Professionals

Interviewee #	Group #	City	Professional Title/Specialty	Agency
1	1	Baltimore	RN- Physical Eval.	Mariner
2	1	Baltimore	RN- IV Infusion	Amicus Infusion Specialists
3	1	Baltimore	Social Worker	Balt. Co. Social Services
4	1	Baltimore	Social Worker	Balt. Co. Social Services
5	1	Baltimore	RN- IV infusion + Wound Care	St. Joe's
6	2	Ft. Lauderdale	Physical Therapist	Care Tenders
7	2	Ft. Lauderdale	RN- Wound Care and Injections	Care Tenders and Broward Home Care
8	2	Ft. Lauderdale	Physical Therapist	Affordable Rehab
9	2	Ft. Lauderdale	Respiratory Therapist	Inferm
10	2	Ft. Lauderdale	RN- Wound Care and IV Therapy	Century Health Services
11	3	Waltham	Registered Nurse	Hallmark VNA
12	3	Waltham	Registered Nurse	Caregroup Home Care
13	3	Waltham	Registered Nurse	Ready Nurse
14	3	Waltham	Registered Nurse	VNA Care Network
15	3	Waltham	Registered Nurse	Hallmark Health

APPENDIX II: Protocols for Informal Caregivers

Participants: ___ **Informal caregivers with home health experience or**
 ___ **Informal caregivers <u>without</u> home health experience**

Interviewer initials: _____ Date: _____ Time: _____

Site: _____

Introduction
Thanks for coming today. Your participation is very important. I'm [first name]. I'm from BearingPoint, an organization that does health-related research. We're conducting interviews for the agency that oversees Medicare.

Project Objective
Today I'm going to show you parts of a website that Medicare is developing to provide information about home health agencies. The website is not finished yet, but we want to get reactions from people to see if we're on the right track.

Interview Process
First I will set you up so that each of you can look at the first website on your own. Then we'll talk about it. The interview will last about two hours.

- Keep in mind that everything you say today will be **confidential.** We will not connect your name with anything you say. Did everyone sign a consent form when they came in today?

- Please keep in mind there are **no right or wrong answers**. This is not a test.

- I am here to learn from you how we can improve this website.

- **You won't hurt my feelings no matter what you day**. So please be honest.

- Do you have any questions before we get started?

Introductions

First, let's introduce ourselves. Tell me a little about yourselves, what you do (or did) for a living, what your family situation is like. **[PROBE briefly re caregiving situation, and if appropriate, prior experience with homecare]**

Laptop set up

Now we can begin. I am going to set up each of you with a computer. Please look through this website about home health care at your own pace, as if you were reading it to look for a home health agency for your loved one. If you see any words or sections that are confusing, make a note of them, so that we can talk about it afterwards. Let me know when you're ready to talk about it.

→ **SET UP EACH RESPONDENT WITH THEIR OWN LAPTOP. WATCH AND RECORD THEIR BEHAVIOR BELOW AND ON THE NEXT PAGE.**

Time reviewed:

Problems with navigation (observed):

Questions and comments made during initial review:

→ NOTE LINKS VIEWED BY RESPONDENTS ON TABLE BELOW.

LINKS	RESPOND'T 1	RESPOND'T 2
Medicare Coverage of Home Health Care		
What is home health care?		
Home Health Quality Measures		
Any of the Quality Measures Listed on Home Page		
More Information About Home Health Quality Measures		
Data Collection Details		
Help with Home Health Search		
Helpful Contacts		
Important Information on Home Health Compare		

Glossary		
"Narrow Your Search" Page		
State Search		
County Search		
Zip Search		
Home Health Agency Name Search		
"Select a Home Health Agency" Page		
"Select a Topic" Page		
"Agency Characteristics" Page		
"Select Quality Measures" Page		
Other links or pages (DESCRIBE)		

→ WHEN RESPONDENTS ARE DONE (OR AFTER 30 MINUTES), SEAT THEM SIDE-BY-SIDE SO THEY CAN DISCUSS THEIR EXPERIENCES.

Warm-up Questions / Overall Impressions

Now we are going to take some time to discuss the website that you just viewed. Tell me about your experiences and share your opinions about the web site.

1. What did you think of this website? Were there any particular parts that you liked or disliked? **[COMPARE AND CONTRAST REACTIONS]**

2. How likely would you be to come back and view this web site again? Why? Would you recommend this web site to a friend who was looking for a home health agency? Why?

3. Was there anything about this website that was particularly confusing? If so, what?

4.   What did you think about the amount of information on this website? Was it too much, too little, or about right?

   IF TOO MUCH-   What was too much?

   IF TOO LITTLE- What did you want more information about? Was there any important information missing from this web site?

   5. Is there anything you would change about how this information is presented on this website?

   → WHEN DISCUSSION DWINDLES, PROCEED TO DETAILED DEBRIEFING THAT FOLLOWS.

HOME HEALTH HOME PAGE

Now let's review the web site together, page by page. We are going to start on first page of the website.

   6. What were your first impressions of this page? Did anything catch your eye?

   7. When you first saw this page, did you read it or did you skip over it and go to the next section?

8.   If you saw this web-page while you were browsing the internet, how interested would you be in continuing to read this page? What makes you say that?

9.   What questions did you have when you first looked at this section?

10.   When you first looked at this, did you click on the link for "What is home health care?"

___ Yes
___ No. (Have respondent(s) review it)

11. Did you find this section helpful? Tell me, in your own words, what it says.

12.   Did you notice the items listed in the section called, "Home Health Quality Measures"? Did any of these catch your attention? If so, which ones and why?

STEP 1: SELECT A GEOGRAPHIC AREA

Now we are going to the next page. The web site requires you to pick a state before you can go on. We're going to pick Wisconsin, just so we're all looking at the same thing.

→ HAVE RESPONDENTS PICK STATE =WISCONSIN AND PRESS "RETURN RESULTS." HELP RESPONDENTS DO THIS, IF NECESSARY.

→ NOTE ANY NAVIGATIONAL PROBLEMS BELOW.

PROBLEM WITH:	RESPONDENT 1	RESPONDENT 2
Drop Down Box		
Scrolling		
Other feature (Describe)		

16.   **Now, you'll see that you have several options for narrowing your search. Which of the options for narrowing your search do you find most useful?**

SEARCH TYPE	RESPONDENT 1	RESPONDENT 2
State		

County		
Zip code		
Name search		

Why?

17.   Which of the options, do you think is least useful?

SEARCH TYPE	RESPONDENT 1	RESPONDENT 2
State		
County		
Zip code		
Name search		

Why?

18.   When you first looked at this page, did you read the section called, "**Read This**"?   **[IF NOT, ASK RESPONDENTS TO READ IT NOW.]** How useful is this information?

USEFULNESS	RESPONDENT 1	RESPONDENT 2
Not useful at all		
Somewhat useful		
Extremely useful		

Why?

19.   Did you see the link called, "**Help with Home Health Search**"? If not, click on it now and take a look. Do you find this information useful?

SELECTION EXERCISE

Now I am going to ask you to pretend that you are siblings.   Your mother has health problems and needs home health services for **[SELECT: hip replacement/ heart disease/ diabetes]**.   She lives in lives in Milwaukee Wisconsin, and you are not familiar with agencies there. But you have heard that Medicare has a web site with information about home health agencies, and you are going to look at that web site to get information about HHAs in Milwaukee County.

→   **HAVE RESPONDENTS SELECT A COUNTY=MILWAUKEE AND PRESS "DISPLAY RESULTS"**

SELECT A HOME HEALTH AGENCY PAGE

20.   Take a few minutes to look over this information. Is there anything else that would be useful to put here?

HH INFO	RESPONDENT 1	RESPONDENT 2
Mentioned phone #		
Other suggestions		

→ HAVE RESPONDENTS SELECT ALL

SELECT A TOPIC PAGE

Now I am going to let you choose a home health agency based on the information available here. Again pretend you are siblings and need to agree on which agencies would be best for your mother who has **[SELECT: hip replacement/ heart disease/ diabetes]**.

21.   Tell me which one you selected and how you did so. [NOTE WHETHER WHAT THE RESPONDENTS REVIEW AND WHAT THEY DISCUSS.]

22.   How helpful was the information shown here in helping you decide which agencies were doing a good job?

STRUCTURED DISCUSSION OF QUALITY MEASURES PAGES

Now I would like you get your thoughts on the Quality Measures.

31.   What is the paragraph, "**What Are Home Health Agency Quality Measures**?" telling you (in your own words)? Is this information helpful? Did you have any questions after reading it?

QUALITY MEASURE BAR GRAPHS PAGE

Take a few minutes to look over these pages.

32.   What are the bar graphs showing you?

33. Which agency is doing the best job at [selected measure]?

→ **NOTE CORRECT AND INCORRECT INTERPRETATIONS OF DATA BELOW.**

34.   Which HHA(s) seemed as if they might have some problems? How did you make that decision?

36.   How helpful was the information shown here in helping you decide which agencies might have some problems?

37.   Looking at the explanatory paragraphs below the bar graphs, do you think the amount of information displayed there is too much, too little, or about right? Do you think the information is useful?

38.   Looking at "Percentage of patients who stay the same (don't get worse) at bathing," do you think that the differences between the agencies are important?   Why or why not?

39. Looking at "Percentage of patients who need urgent, unplanned medical care," which agency is doing the best job? Why do you think that? **[NOTE WHETHER RESPONDENTS ARE CONFUSED BY SWITCHING FROM POSITIVE TO NEGATIVE MEASURES]**

40. Did you notice that for some home health agencies, such as HHA AOG, the bar graphs say "Not available"?   What did you think that means?

"Not Available" means	RESPONDENT 1	RESPONDENT 2
DATA IS NOT AVAILABLE.		
HHA IS NOT AVAILABLE.		
OTHER		

41. Now, let's look at the bar graphs for "Percentage of patients who get better at getting in and out of bed." What did you think about the wide range of scores? How would you explain this to a friend or family member?

RANKING OF QUALITY MEASURES

Now, take a few minutes to think about the quality measures again.   Then write down two or three that seem most important to you, given what you know about home health care.

11.   Which ones did you pick [as most important]? [RECORD RESPONSE] Why do you think these are important?

Now pick two or three measures that don't seem that important to you.

11.   Which ones did you pick that don't seem that important? [RECORD RESPONSE] Why do these not seem so important?

Now, if you click on the measures you chose, you'll see a definition of the measure and why it may be important. Click on one of the measures you chose as important and look over what it says there. [HELP RESPONDENT DO THIS, IF NECESSARY]

12.   Does this agree with what you thought before? Was this explanation easy to understand? Was it helpful? [RECORD COMMENTS, SUGGESTIONS IN BOX]

Click on one of the measures you didn't think was that important and look over what it says.

13.   Was this explanation easy to understand? Did it change the way you were thinking about this? [RECORD COMMENTS, SUGGESTIONS IN TABLE ON NEXT PAGE.]

MEASURE	SUGGESTED IMPROVEMENTS
Percentage of patients who get better at getting dressed	
Percentage of patients who get better at bathing	
Percentage of patients who are confused less often	
Percentage of patients who get better at taking their medicines correctly (by mouth)	
Percentage of patients who get better at walking or moving around	
Percentage of patients who get better getting to and from the toilet	
Percentage of patients who get better at getting in and out of bed	
Percentage of patients who have less pain when moving around	
Percentage of patients who stay the same (don't get worse) at bathing	
Percentage of patients who need urgent, unplanned medical care	
Percentage of patients who had to be admitted to the hospital	

14. What did you think about the order in which the measures were presented. Is there a better way to list them? Which items should come first?

15.   Overall, how difficult do you think it is to understand these measures? Do you think they are

___ Very difficult to understand
___   Somewhat difficult
___ Easy to understand

45.   How likely would you be to use this website to compare home health agencies in your area?   Would you recommend it to a family member or friend if they needed home health care?

1   Very likely
2   Not very likely
3   No way, Jose
4   Don't know/not sure

46.   What if anything would you change about how this information is presented on this website?

47.   Do you have any other questions or comments about this website?

END TIME: _____

We really appreciate the time you took to help us today. The receptionist will give you your financial incentive and have you sign a form that says that we paid you for your participation.

APPENDIX III: Protocols for Health Care Professionals

Home Health Compare
Website Usability Testing

Focus Group Moderator's Guide

Participants: **____Discharge Planners or   ___ Home Health Nurses**

Interviewer initials: _____   Date: _____   Time: _____

Site: _____

Introduction
Thanks for coming today. Your participation is very important. I'm [first name] and this is [observer]. We're from BearingPoint, an organization that does health-related research. We're working on this project for the agency that oversees Medicare.

Project Objective
Today I'm going to show you parts of a website that Medicare is developing to provide information about home health agencies. The website is not finished yet, but we want to get reactions from people to see if we're on the right track.

First I will set you up so that each of you can look at the first website on your own. Then we'll talk about it. The interview will last about two hours. I'll be asking you questions about the web site, and [oberserver name] is here to help me take notes.

- Keep in mid that everything you say today will be **confidential.** We will not connect your name with anything you say. Did everyone sign a consent form when they came in today?

- Please keep in mind there are **no right or wrong answers**. This is not a test.

- I am here to learn from you how we can improve this website.

- **You won't hurt my feelings no matter what you day**. So please be honest.

- Do you have any questions before we get started?

- **Introductions**

Before we begin looking at the website, let's go around the table and introduce ourselves. Please state your name, where you work, and what types of patients you work with.

Laptop set-up

Now we can begin. I am going to set up each of you with a computer. Please read through this website at your own pace, as if you were reading it on your own. If you see any words or sections that are confusing, please write them down, so that we can talk about it afterwards. Or if you prefer, you can help each other.   Let me know when you're ready to talk about it.

→ **SET UP EACH RESPONDENT WITH THEIR OWN LAPTOP. THE MODERATOR AND OBSERVER WILL BOTH WALK AROUND TO OBSERVE THE PARTICIPANTS AND RECORD THEIR BEHAVIOR BELOW**

Participant questions and comments:

LINKS VIEWED	Participant 1	Participant 2	Participant 3	Participant 4
Medicare Coverage of Home Health Care				
What is home health care?				
Home Health Quality Measures				
Any of the Quality Measures Listed on Home Page				
More Information About Home Health Quality Measures				
Data Collection Details				
Help with Home Health Search				
Helpful Contacts				
Important Information on Home Health Compare				
Glossary				
"Narrow Your Search" Page				
State Search				
County Search				
Zip Search				
Home Health Agency Name Search				
"Select a Home Health Agency" Page				
"Select a Topic" Page				
"Agency Characteristics" Page				
"Select Quality Measures" Page				
Other links or pages (DESCRIBE)				

→ WHEN RESPONDENTS ARE DONE (OR AFTER 20 MINUTES), GATHER RESPONDENTS
TOGETHER FOR A GROUP DISCUSSION. EVERYONE SHOULD USE THEIR LAPTOP SO
THAT THEY CAN FOLLOW ALONG.

Warm-up Questions / Overall Impressions

Now we are going to take some time to discuss the website that you just viewed. Tell me about your experiences using the web site and we can discuss it as a group.

1. What did you think of this website overall? (PROBE TO SEE IF FIRST IMPRESSIONS ARE POSITIVE OR NEGATIVE)

2.   Was there anything about the website that surprised you?

3.   Were there any parts of the web site that you thought were particularly **useful**?
       [NOTE if they bring up checklist or other sections.]

4.   Was there anything in particular on this website that you thought was **confusing**? Was there anything about
       it that you did not like?

5.   Was there anything, besides what you've mentioned, that you think the average consumer would find
       confusing? If so, what?

6.   How likely would you be to come back and view this web site again?   Why?

7.   What did you think about the amount of information on this website? Was it too much, too little, or about
       right?

       __ Too much. What should be removed?

       __ Too little. What else was needed?

8.   Is there anything you would change about this website?

→ WHEN DISCUSSION DWINDLES. TURN ON PROJECTOR AND REVIEW THE WEB SITE
   WITH PARTICIPANTS, PAGE BY PAGE.

HOME HEALTH HOME PAGE

Now we are going to go through the web site page by page to get your comments on specific sections. Keep your laptop on and follow along with me.

7.   Looking at the first page of the website, did anything catch your eye? (What were your first impressions of this page?)

8.   What questions did you have when you first looked at this section?

9.   When you first looked at this site, did you click on the link, "What is home health care?"

___ Yes
___ No. (Have respondents review it)

10.   Do you think this will help consumer understand what home health care is? Is there anything here that is likely to confuse consumers?

11.   Did you notice the items listed in the section called, "Home Health Quality Measures"? Did any of these catch your attention? If so, which ones and why?

STEP 1: SELECT A GEOGRAPHIC AREA

→ **PICK STATE=WISCONSIN**

STEP 2: NARROW YOUR SEARCH PAGE

26.   Which of the options for narrowing your search, do you think are <u>most useful</u>? Why?   Are there other search options that you would find useful?

27.   Which of the options, do you think is <u>least useful</u>? Why?

28.   When you first looked at this page, did you read the section called, "Read This"?   How useful is this information?

29.   Did any of you click on the link called, "**Help with Home Health Search**"?   If so, did you find the information useful? Is there anything we do to make this more helpful?

→ **SELECT A COUNTY=MILWAUKEE. PRESS DISPLAY RESULTS**

STEP 3: SELECT A HOME HEALTH AGENCY PAGE

→ **SELECT ALL**

STEP 4: SELECT A TOPIC PAGE

→ **SELECT "VIEW AGENCY CHARACTERISTICS"**

AGENCY CHARACTERISTICS PAGE

30.   Take a few minutes to review the information displayed here. What do you think of this information? Do you think most consumers would find this helpful?

31.   Is there anything that could be improved about this page? (NOTE IF RESPONDNETS SUGGEST ADDING PHONE #s)

→ **RETURN TO SELECT A TOPIC PAGE**

→ **SELECT QUALITY MEASURES**

SELECT QUALITY MEASURES PAGE

Now I am going to ask you to select one or two home health agencies that you think are good performers and one or two that are bad performers based on the quality measures listed here.

You can select as many or few quality measures as you like. Some may want to look at only the measure that is most important. Others may want to look at the agencies performance on all measures.

When you are done looking at the quality measures you selected, write it down the best and worst performers down on your paper. Then we will discuss our choices as a group.

→ **NOTE RESPONDENT BEHAVIOR OR COMMENTS BELOW:**

34.   Are there one or two agencies that stand out as especially good performers, based on this information?
        What makes them stand out, in your view?
        [NOTE WHICH QMS ARE MENTIONED AND GIVE MOST WEIGHT.]

35.   Are there one or more agencies that you would have particular concerns about, based on this information?
        What would you be concerned about?
        [NOTE WHICH QMS ARE MENTIONED AND GIVEN MOST WEIGHT.]

36.   How difficult was for you it to review all the QMs and make a decision? Do you think the average consumer would have a difficult time reviewing the QMs and making a decision?

DETAILED FEEDBACK ON QUALITY MEASURES

Now let's go back and review the list of quality measures and talk about them.

36.   Do any of these measures seem like they would not be useful for assessing the quality of home health agencies? Why? (Allow participants to compare and contrast.)

37.   What did you think about the order in which the measures were presented?   Is there a better way to list them? (PROBE: for example, in alphabetical order, or by frequency of the condition?)

38.   How difficult do you think it would be for your average consumer to understand these measures as they are listed here? (NOT LOOKING AT DEFINITIONS)
___ Very difficult to understand
___Somewhat difficult
___ Easy to understand

39. Now let's click on the definitions of the measures. Is there anything we can do to make them easier for consumers to understand?

MEASURE	SUGGESTED IMPROVEMENTS
Percentage of patients who get better at getting dressed	
Percentage of patients who get better at bathing	
Percentage of patients who are confused less often	
Percentage of patients who get better at taking their medicines correctly (by mouth)	
Percentage of patients who get better at walking or moving around	
Percentage of patients who get better getting to and from the toilet	
Percentage of patients who get better at getting in and out of bed	
Percentage of patients who have less pain when moving around	
Percentage of patients who stay the same (don't get worse) at bathing	
Percentage of patients who need urgent, unplanned medical care	
Percentage of patients who had to be admitted to the hospital	

Now, take out a clean piece of paper, please list the measures from most important to least important. When you are done, please put down your pencil and we will discuss it.

40.	Which measures did you pick as most important? Why? (COMPARE AND CONTRAST)

41.	Which measures did you pick as most important? Why? (COMPARE AND CONTRAST)

42.	Looking at "Percentage of patients who stay the same (don't get worse) at bathing," do you think that the differences between the agencies are important or significant? Why or why not?

43.	Looking at the explanatory paragraphs below the bar graphs, do you think the amount of information displayed there is too much, too little, or about right? Do you think the average consumer would find it understandable and useful?

44.	Did you notice that for some home health agencies, such as HHA AOG, the bar graphs say "Not available"? What did you think about that? How did you interpret that? [PROBE TO DETERMINE WHETHER THEY BELIEVE DATA OR HHA IS NOT AVAILABLE.]

LIKELINESS TO USE

40.	How likely would you be to use this website if it were up and running?

	IF NOT VERY LIKELY – Why not? What might change your mind?

	IF LIKELY - What would you most likely use it for?

43.   How likely would you be to refer patients or their caregivers to this site?

<u>CLOSING</u>

43.   Do you have any other questions or comments about this website?

END TIME: _____

We really appreciate the time you took to help us today. The receptionist will give you your financial incentive and have you sign a form that says that we paid you for your participation.

Again, thanks very much!

APPENDIX IV: Recommended Questions for the Home Health Care Checklist

Questions about care

- How soon will someone come to my house?

- How often will the nurse/therapist/aide come to my home?

- How many total visits will there be and over what period of time?

- How long should I expect each visit to last?

- What are reasonable expectations about home health for myself/my loved one in my/their situation?

- What services will the agency provide and what can't/won't they provide?

- Who will I be seen by, a nurse or an aide?

- Will I have a male or female nurse?

- Can I change nurses if I don't like the one I have?

- What is the continuity of care? Will I have one nurse/therapist/aide or a different person each time?

- How do they set up schedule of visits? Is the time of the visit flexible?

Questions about the home health agency staff

- What are the staff ratios (nurses vs. aides)?

- What is the patient load of each nurse/therapist?

- What is the turn-over rate of the staff?

- Do they perform background checks on employees?

- What kind of supervision is there of the staff?

- How many years of experience for each nurse/therapist/aide?

- What are the languages spoken by staff (including if they are fluent in English)?

- What is the education background and licenses held by each staff member?

Questions about the agency

- Is the agency bonded? Is the agency licensed?

- Have there been any formal complaints made about the agency?

- Have there been any citations against the agency?

- Are there any complaints against the agency currently being investigated?

- How are complaints handled?

- Can they agency give me the names of previous patients I can call for a referral?

- Does this agency contract out for services or have in-house staff for OT, PT, etc?

- Is there a 24 hour on-call number for emergencies?

- Does the agency provide any follow-up services after the termination of home health services?

- What are my rights to appeal a discharge?

- What procedures does the agency have for reducing medical errors?

- What services/information is provided to family members?

- What is the back-up system? If my regular nurse can't come will they send someone else or will I have to wait?

APPENDIX V: Specific Recommendations "Home Health Compare" Website

Short Term Changes

The following are suggestions about how the "Home Health Compare" Website can be enhanced in the short tem. All are based on feedback received during consumer testing of the website prototype in February 2003.

HOME PAGE

- Provide more explanation about what Quality Measures are and how to use them to evaluate home health agencies. Use the same language contained in the "More Information About Home Health Quality Measures" page as follows:

> **Home Health Quality Measures** give you information about how well home health agencies provide care for their patients. The measures provide information about patients' physical and mental health, and whether their ability to perform basic daily activities is maintained or improved. Quality information can be used to help you compare home health agencies. Click here for **More Information about Home Health Quality Measures**.

- Create new language to emphasize the difference between home health care that is covered by Medicare (i.e. after acute care, limited in time and scope) and custodial and long-term care in the "What does Medicare cover" page. Emphasize that patients are usually expected to get better on Medicare-covered home care, but that they are not usually expected to get better on custodial or long-term care. Make the link between these expectations and the quality measures relating to improvement.

- Add the "Checklist" link to the home page – and consider adding it to other pages throughout the web site to make it more prominent. (Note: Virtually all respondents thought the checklist would be helpful, but almost none noticed the link in its current location.)

"WHAT DOES MEDICARE COVER" PAGE

- Rework "What does Medicare cover" to be more clear and concise, summarizing eligibility and services covered from language in the Medicare and Home Health Care booklet. (Note: This was one of the first links many respondents clicked on.)

- Describe eligibility criteria as in Medicare and Home Health booklet, using and explaining the concept of "homebound."

- Include information about what Medicare does not cover, also summarized from the booklet. If possible, direct readers to state's Medicaid agency for information about additional home health coverage.

"SEARCH BY AREA" PAGES

- Add steps to the search tool (similar to those in Nursing Home Compare)

- Change title "Select a Geographical Area" to "Search for home health agencies by area." (Note: Respondents did not recognize that this link was the beginning of a search for agencies. Many expected to find more information about a given geographical area, such as Medicaid coverage.)

- Move "Help with home health search" up the page, to be next to the search tool.

- Move "County Search" (most useful) to top of Narrow Your Search page. Move "State Search" (least useful) to bottom.

- Consider adding "City Search" as an addition to or replacement for "County Search." (Note: Many do not know the county, especially when searching out of state.)

- Widen scope of "Zip Code Search" to include neighboring zip codes (ideally listing all agencies that serve a specified zip code). The current search yields only those agencies with the specified zip code in the mailing address, which is too narrow to be useful.

- Move "Next Step" button to directly below list of agencies displayed on the "Select a Home Health Agency" page, and directly below the list of measures displayed on the page where user selects measures to view on bar graphs. Leave the "Select All" and "Reset" buttons at the top of the lists (see protocol). (Note: When "Select All" button is located at the bottom of the list, users often inadvertently click this after spending time selecting specific options and become frustrated.)

"AGENCY CHARACTERISTICS" TABLES

- Include phone numbers for agencies along with addresses if possible.

- Change "Medical/Social Services" to "Social Services." (Note: Readers often misinterpret the former label assuming this refers to medical and social services.)

- Provide some information on difference between private vs. non-profit vs. government ownership of agencies. (Note: Many consumers think "private" means "self-pay.")

- Add "date last updated" to information in the characteristics tables. (Note: Many users question how current the information is.)

QUALITY MEASURES PAGES

- Rework the explanations of the quality measures (found in the links from the list of QMs and between each graph) so that the first paragraph clearly describes the impact home health care has on that indicator. [This language is frequently found in the middle or later paragraphs of the current explanations.] For example:

> **Patients who get better at taking their medicines correctly (by mouth)**
>
> **Why is this information important?**
> Home health staff can help teach you ways to organize your medicines and take them properly. Getting better at taking your medicines correctly means the home health agency is doing a good job teaching you how to take your medicines…

- Change "Not Available" in graphs to "Data not available" and rework footnote explanation. (Note: Many respondents interpreted "not available" to mean "services not available.")

- Replace "Rate" in "Phase I States Rate" and "[STATE] Rate" to "Average"

- Include total number of patients included in agency percentages on graphs. (Note: Many respondents questioned the numbers, especially when percentages displayed were very low or very high.)

- Change the label for the toileting measure. Many consumers mistake this as a mobility measure only. Consider "Patients who get better at using the toilet on their own."

- Add "date last updated" to information in the display tables.

- Hide most of text between graphs, leaving just the first paragraph that explains how home health agencies can have an affect on this measure. Put the rest on a page that users can access with a link. For example:

Patients who get better at taking their medicines correctly (by mouth)

[Bar Graph Here]

What does this mean?

- The percentage of patients who get better at taking their medicines correctly. The measure includes only medicines the patient takes by mouth.

- Higher percentages are better.

Where do these numbers come from?

Why is this information important?
Home health staff can help teach you ways to organize your medicines and take them properly. Getting better at taking your medicines correctly means the home health agency is doing a good job teaching you how to take your medicines. **Click here more information.**

- Clarify explanation of the interpretation of bar graphs relating to adverse outcomes by referring to state and national (or Phase I) averages. (Note: many respondents become confused by discrepancy between current information that states "lower percentages are better" and language in explanation that states some admissions or emergencies are unavoidable.) For example:

Percentage of Patients Who Had to be Admitted to the Hospital

What does this mean?

- The percentage of patients who had to be admitted to the hospital.

- The state and national averages indicate the average number of home health patients who have to be admitted to the hospital. Home health agency percentages that are much lower *or* much higher than the state average should prompt further questions (see below).

Why is this information important?

Some inpatient hospital care may be avoided if the home health staff is doing a good job at checking your health condition at each visit to detect problems early. They also need to check how well you are eating, drinking, and taking your medicines, and how safe your home is. Home health staff must coordinate your care. This involves communicating regularly with you, your informal caregivers, your doctor, and anyone else who provides care for you.

However, patients may need to go into the hospital while they are getting home health care. In some instances, this may not be avoidable even with good home health care. For instance, some illnesses are not curable and, over time, will make your health worse. For some patients, a readmission to the hospital may be a planned part of continuing treatment for their medical conditions. Good home care may also detect the need for a hospital admission.

"Frequently Asked Questions" Section

Consumer testing revealed that consumers making home health decisions frequently inquire about the following topics:

Medicare Coverage

- What home health care services does Medicare cover?

- How do I know if I am eligible for Medicare-covered home health care services?

- What home health costs does Medicare NOT cover? Where can I find information about home health services that are not covered by Medicare?

- How much will I have to pay out of pocket?

- Where can I get assistance with the costs that Medicare does not cover?

- Do you have to pay more for a private home health agency than for a governmental or non-profit agency?

- What is the difference between what Medicare and what Medicaid covers?

Home Health Basics

- How is home care arranged? Who can arrange home care if I need it?

- Where do I go to get home health care? Can a friend or family member arrange for home care on their own if they think a Medicare beneficiary needs it?

- Do I have a choice of home health agencies?

- How long can I expect to receive home health care?

- What sort of services should I expect/look for?

- For how long do Medicare beneficiaries receive home health services on average? How many times on average do home health agency staff visit patients, for how long?

- Do physicians oversee the home health care services? If so, how do they do so and how frequently?

- Where do I go if I have a complaint about my home health care?

- Where else can I go for help if I need it?

- How can I make my family member will be safe when receiving home health services? (Many caregiver respondents stated that many Medicare beneficiaries do not feel safe having "strangers" such as home health workers in their home.)

- Where can I find information about patient staff ratios and staff qualifications? (This should also be part of the checklist.)

- What do I need to know before choosing a home health agency? What are the pitfalls that I should avoid?

- What can I do if my home health care ends and I still need help?

- Where can informal caregivers find information about respite care?

Quality of Home Health Agencies

- Where can I get information about the quality of home health care agencies?

- Where can I go to find out if there has been a formal complaint made about a home health agency?

- Where can I find out whether the home health agency is certified and the staff is bonded and has a thorough background check to screen for incidents of theft, abuse, or neglect? (This should also be part of the checklist.)

- What do the quality measures tell me about a home health agency?

- Why do the quality measures emphasize "getting better" when many home health patients can't get better?

- Do private home health agencies provide better care than governmental or non-profit agencies?

- Do you I know that these quality measures and statistics aren't skewed or comparing apples to oranges?

GLOSSARY

Participants in the consumer testing of the HHC website prototype rarely asked the researchers to explain specific words. Nevertheless, our results suggest that consumers may misinterpret or be confused by the following terms:

- Homebound

- Skilled care

- Private, non-profit, government ownership

- Medicare certification

- Rehabilitation

- Intravenous therapy

- Nebulizer

- Risk adjusted

- State Qualify Improvement Agency

- Speech Pathology

- Dementia

Long Term Changes

The following are suggestions about how to enhance the effectiveness of the home health quality initiative over the long term.

- Focus education campaign on the types of home health care that are covered by Medicare, what quality measures are, and how consumers should use them.

- Consider rewording the emergent care and hospitalization measures. Many consumers interpret these as indicators of agency responsiveness (good agency performance) rather than signs of inadequate care (poor agency performance).

- Add links to information about custodial, long-term care and respite care.

- Consider removing or rewording the "stayed the same at bathing" measure. Most find it to be redundant, and less understandable than the improvement in bathing measure.