

University of Maryland Center on Aging

*Medicare/Medicaid
Integration Project*

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Designing Effective Survey Methods for Frail Elders

Symposium Proceedings

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The Medicare/Medicaid Integration Program

The purpose of The Robert Wood Johnson Foundation (RWJF) Medicare/Medicaid Integration Program (MMIP) is to end the fragmentation of financing, case management, and service delivery that currently exists between Medicare and Medicaid. States are provided with grant support and technical assistance in their efforts to restructure the way in which they finance and deliver acute and long-term care. Technical assistance focuses on those states that have been awarded grants but is not limited to grantees. It is recognized that other states and initiatives can benefit from this help.

The Foundation staff responsible for the program are: Nancy Barrand, Senior Program Officer; Pam Dickson, Senior Program Officer; James Knickman, Ph.D., Vice President for Research and Evaluation; and Diane Montagne, Program Assistant. The National Program Office (NPO) for the program is based at the University of Maryland Center on Aging under the direction of Mark R. Meiners, Ph.D. The NPO provides technical assistance and direction for the initiative. Margaret Schulte is the Deputy Director for the program.

Information about the MMIP can be obtained from the following locations:

Website: <http://www.inform.umd.edu/aging>
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New England States Consortium (NESC)

In May 1995, representatives of the six New England Medicaid programs met with representatives of the Health Care Financing Administration (HCFA) to discuss common issues and concerns. A major focus of attention was on the needs of persons eligible for both Medicaid and Medicare. Dually eligible persons include primarily older persons and persons with disabilities who utilize a significant portion of the state Medicaid resources even though they have extensive federal coverage under Medicare. Indeed, the states' representatives believe that the lack of integration between these two major health programs increases costs for both programs without necessarily improving care.

This simple meeting sparked the establishment of the New England States Consortium as an organizational structure "to coordinate activities related to the design, implementation, operation and management of a program for the delivery of comprehensive, coordinated care to persons who are dually eligible for Medicaid and Medicare" (*New England States Consortium, Memorandum of Understanding 12/26/96*). The Consortium has several work groups to focus discussions between the member states and HCFA on specific issues.

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Purpose

On December 7 and 8, 2000, state and federal policymakers met together with researchers to discuss effective methods for surveying frail elders regarding their health care experience. This Invitational Symposium was sponsored by the Medicare/Medicaid Integration Program (MMIP) at the University of Maryland's Center on Aging as an opportunity to learn from multiple survey initiatives about the value and limitations of using standard instruments and methods to solicit feedback from frail elders. The meeting was designed as an informal exchange of ideas and insights that could help policymakers and researchers better understand the factors that enhance and impede hearing the voice of this population. These Proceedings synthesize discussions on major issues addressed throughout the two-day meeting.

Background

In 1996, The Robert Wood Johnson Foundation and the University of Maryland Center on Aging established the Medicare/Medicaid Integration Program to assist states in developing integrated approaches to the provision and payment of services for Medicare and Medicaid beneficiaries. Since that time, thirteen states have been recipients of grant awards to develop innovative strategies to better manage and coordinate services to older persons and persons with disabilities. Some of these programs focus on Medicaid with coordination of Medicare benefits, while others, through waiver arrangements with the Health Care Financing Administration (HCFA), integrate both Medicaid and Medicare services and payments. All of these programs examine ways to improve the spectrum of acute and chronic care services at the consumer, provider, and payor levels.

Consumers have more at stake under these programs since decisions made on their behalf influence not only their health but frequently how or where they spend their lives and what life opportunities are facilitated or precluded. Assuring that consumer views are integrated into program decision-making processes is a major challenge. One aspect of a consumer-centered approach is the periodic solicitation of consumer feedback regarding their experiences under the program.

There are few tools available to state program administrators to solicit consumer feedback. One of the most prevalent consumer surveys is the Consumer Assessments of Health Plans Study (CAHPS) instrument developed under the sponsorship of HCFA and the Agency for Health Care Research and Quality (AHRQ). This set of standardized and tested survey questionnaires is broadly used by private purchasers, HCFA currently requires all Medicare risk and cost contractors to use it, and in some cases, it has been required as a condition of waiver approval under Medicaid.

Two years ago, the New England States Consortium (NESC)¹, under contract with the Braceland Center for Mental Health and Aging, administered a modified CAHPS survey instrument to assess its applicability for community-based frail elders. Surveys were administered using mail, telephone and in-person modalities. While the CAHPS survey had been tested among the elderly in general, little was known about its utility for elders who have one or more cognitive or sensory limitations, or for whom chronic illness, fatigue, fear, or class differences would play a role. The NESC pilot study identified many challenges to surveying frail elders, especially as they relate to problems with

¹ A collaborative of the six New England States funded under the RWJ MMIP initiative to serve as an organizational structure for coordinating activities for persons dually eligible for Medicare and Medicaid.

hearing, comprehension, estimation and the general tendency to respond in socially desirable ways. Other researchers have reported similar findings on the use of survey methods generally with this population (see Appendix A for a literature review).

The concept for an Invitational Symposium arose out of two concerns. First, with the movement to design service systems for frail elders, there is growing need for reliable tools for assessing consumer views on how the programs are meeting their needs. State and federal policymakers need to better understand any limitations associated with these tools to inform program choices. Second, there was interest in providing a forum for researchers and policymakers to examine obstacles to using conventional survey methods among frail elders and to consider alternative approaches or improvements.

Organization of the Report

This Report summarizes major issues addressed during the two-day Invitational Symposium. Although the content of the discussion has not been changed, liberties have been taken to re-organize discussion into the following major themes:

- Purpose and Use of the Survey Data
- Constraints to Measurement
- What to Measure
- Special Considerations for Survey Design and Methods

Efforts were made throughout the Symposium to identify areas where there is broad consensus on an issue. While this was not always possible, the Conclusion highlights areas where there was general agreement.

The Symposium began with presentations on three very different initiatives to survey frail elders living in the community or in nursing homes. These presentations provided the backdrop to discussions which followed on specific challenges and strategies for designing and executing effective survey approaches for frail elders. Readers are encouraged to refer to Appendix B for a summary of these initiatives.

Purpose and Use of the Survey Data

A recurring theme throughout the meeting was the need to have a clear understanding of the purpose and use of the findings before designing a survey instrument. Four potential purposes were defined, each quite different with respect to the types of questions and analyses that would be required:

- **Accountability:** assessment of whether a service delivery system is fulfilling the terms of its contract or other requirements.
- **Evaluation:** determination of whether a given mode of service delivery is effective in meeting predetermined objectives and/or in comparison to other delivery types.

- **Quality improvement:** identification and tracking of areas for improvement.
- **Consumer education:** reporting specific areas of service performance of interest to consumers in selecting among service delivery options.

Generally it was agreed that end-users either give inadequate consideration to the primary purpose for collecting survey data or have multiple and potentially conflicting purposes for conducting a survey. Many factors compromise a pure research approach to surveys: competing state/federal interests in survey data, the high costs of administering surveys, and the desire to reduce burdens placed on beneficiaries to complete multiple surveys. Thus, for example, the CAHPS survey instrument is used or modified by some states to hold contractors accountable while at the same time to satisfy HCFA's priority to inform beneficiaries on how other consumers rank their health care programs. Designers of the CAHPS instrument focused on its use by consumers and purchasers to compare performance across a broad array of delivery systems. Its applicability for accountability or quality improvement purposes may be restricted given that questions are not specific to a given model of care.

Failure to define a clear purpose for a survey can lead to the inappropriate use of survey findings. Technical limitations of the questions, sampling methods, survey administration, or data analyses may reduce the reliability of findings. The possibility of "over-reaching" in drawing conclusions from the data may be exacerbated when policymakers rely on analytic reports prepared by vendors or third parties without knowing how survey responses were collected, coded, or analyzed. Given the critical role played by vendors, participants underscored the importance of selecting vendors who can demonstrate their abilities to translate policymaker objectives into reliable survey instruments and data analyses that support those objectives.

Survey findings also are used inappropriately when findings are associated with a specific program or system of care that is not contractually accountable for affecting the outcome. For example, consumer survey findings may indicate that beneficiaries enrolled in Medicaid home and community-based services (HCBS) waiver programs report the lack of timely access to physician services. Since physician services are Medicare-covered services for most waiver enrollees, Medicaid HCBS programs have limited clout to address identified deficiencies

Prior to survey administration, careful and explicit consideration should be given to the ultimate use of data, including the types of analyses and reports that can and cannot be supported through the research methods. While not a safeguard that others will not use the data to impute inappropriate conclusions, such statements will set upfront parameters for vendors and policymakers in defining the purpose and use of data.

Constraints to Measurement

The following characteristics of the frail elder population underscore both the challenges and the imperative to design survey instruments and techniques that take into account their special needs.

Identifying and locating frail elders. Nursing home residents and beneficiaries enrolled in state Medicaid Title XIX HCBS waiver programs are the most typical populations identified as frail elders. Many states have developed integrated or other programs whose enrollees include frail

elders, others include a combination of well and frail elderly. Others may reside in the community and go undetected with respect to the degree of their frailty. Frail elders move frequently among settings of care (e.g., home, hospital, nursing home, HCBS waiver program) which compounds problems in identifying the population and conducting longitudinal studies.

Legal representatives. Frail elders may have guardians, power of attorney, family members, or other gatekeepers whose permission may be necessary before a beneficiary can participate in a survey. Time and effort is required to identify these individuals prior to survey administration to gain their approval for participation of the elder.

Cognitive impairment. A major challenge in surveying frail elders is to hear the voice of people who have difficulty expressing themselves due to dementia or mental illness. Too often those who are able to respond to survey questions mistakenly become representatives for those who cannot speak for themselves. Excluding frail elders with cognitive impairments and limiting surveys to only those who can report may provide false assurances to policymakers and produce perverse incentives to providers to neglect the needs of persons with cognitive impairments. Innovative and creative strategies are required to capture the experiences and sentiments of the entire segment of persons served by programs.

Cognitive energy and motivation. Age and infirmity affect the willingness or ability of frail elders to work hard to answer a question or to complete a survey. When frailty is combined with the usual constraints of the elderly, the result is a population that is uniquely difficult to survey. Because of their unique difficulties, strategies that are unnecessary with other populations must be included if surveys of this population are to produce useful results.

Fatigue. A major constraint in doing survey research with frail elders is the physical and cognitive stamina required to withstand the survey process. Lack of energy may cause respondents to dismiss complex questions, answer incorrectly or terminate a survey. The fatigue factor reinforces the value of face-to-face interviews, in lieu of written or telephone interviews, where the impact of fatigue can be detected. It also cautions against including complex questions and items that lengthen the survey and for which other data sources may be available.

Comprehension/Literacy Level. Low educational levels of frail elders complicate the informed consent process and survey administration. Survey questions often include language not in general use among frail elders. Concepts such as “referral”, “specialist”, or “health plan” are frequently not understood and exacerbate confusion, anxiety, and fatigue.

Social/Class distance. Research from the 1950s found that the perception of social distance between the interviewer and person being interviewed affects survey response. This has particular relevance to surveys of frail elders where there are likely to be significant disparities between interviewer and respondent. According to the research, respondents are more apt to act positively when language and imagery are within a context that is familiar to them. Similarly, people tend to react negatively when they are in doubt about what is being asked. Research suggests that speech, ways of ordering experiences, and the ability to take multiple perspectives are all influenced by social class.

Response bias. Poor and frail elders generally feel very grateful for the care they are getting and are not inclined to say anything critical of their care, caregivers or providers. The fear of retribution

is high and generally frail elders distrust the confidentiality of the data collection process. In addition, older adults are more likely to provide acquiescent responses that can also bias survey results. (Please refer to Appendix A, item 3 for a discussion regarding socially desirable response bias and item 4 for a discussion regarding acquiescent response bias).

Estimation/Recall. Studies have found that the ability of most people to recall health-related events that have happened in the recent past is limited. Recall among frail elders tends to be even more inaccurate. Questions requiring frail elders to recall the frequency of service use or the last time they saw their physician create anxiety among frail elders who view such questions as a test on how well they can answer a question.

What to Measure

Policymakers are often tempted to incorporate all facets of a program's operation and areas of potential interest into a single survey. There were three issues identified with respect to the number and types of questions included on survey instruments.

Duplication. Survey instruments often include data elements that can be obtained from other sources (e.g., claims and eligibility files, assessment data, charts). In addition to adding to the length of a survey and the associated energy required to complete it, such questions send the message that one part of the program does not communicate with the other. Despite the complexity of linking other data sources to specific survey respondents, policymakers are strongly encouraged to do so. Making use of available data not only reduces the length of a survey and thus the burden to respondents but also eliminates beneficiary frustration with providing information that should have already been known by the survey sponsor.

Policymakers should consider survey research as only one of many tools available for soliciting beneficiary feedback and monitoring quality. Surveys should be part of a broader quality management system that may also include focus groups, service call-backs, service evaluation response cards, variation analyses and focused studies. The length of surveys for frail elders might be shortened if other modes of information collection (e.g. focus groups) were used when appropriate.

Relevance. Many survey instruments are designed to collect information that policymakers believe is associated with quality of care. These factors may or may not be the same as what consumers consider important in selecting a service delivery system or, once having enrolled in a program, in assessing their experience with the program. Research shows that the relevance of questions to respondents affects their willingness to participate and to complete interviews as well as the extent to which they are willing to "work" to provide complete and thoughtful answers. When the respondent has not thought about particular issues before, they are more likely to provide an acquiescent response or the response choice they perceive as being "right." At the front-end, policymakers must be clear about whose voice they are trying to capture and to involve those stakeholders in the design of surveys. Tensions exist among what beneficiaries want to talk about, what caregivers and providers need to know to improve services, and what policymakers deem important for accountability. If the issues are irrelevant for consumers, policymakers and providers may have to accept reduced response rates as a consequence.

Focus. If the purpose of the survey is to assess program effectiveness and/or identify quality improvement areas, surveys should be specific to the requirements, benefits, and populations of a given service delivery system (e.g., home and community-based waiver, fee-for-service, nursing home, integrated delivery system). Separate surveys could be designed with a set of core questions that apply across delivery systems and specific questions applicable to a given program. Alternately, surveys can be used to assess the experience of the frail elderly across delivery systems, where the focus includes areas of more general interest to policymakers and/or consumers.

Special Considerations for Survey Design/Methods

The complexity of the population creates a daunting task when trying to construct and implement instruments and methods for surveying frail elders. Much work remains to be done to develop standardized approaches appropriate to the full range of elders with cognitive and physical impairments in all settings of care. However, meaningful work that is currently being done in this area can be instructive to others and to a future research agenda.

Well versus frail elderly. The frail elderly represent a distinct subset of the elderly population with very different needs, expectations and experiences with the health care system. Separate surveys for the well and frail elderly were advised.

Face to face interviews. Many factors mitigate against the use of mail or telephone methods for surveying frail elders. Difficulties in hearing and comprehension during telephone interviews may render them ineffective, whereas such impairments might be accommodated when an interviewer is face to face with the respondent. Heavy reliance on proxies (see below) and low response rates reduce the value of mailed surveys. Face to face surveys have the advantage of incorporating assistive communications devices and materials to include those without telephones (such as many nursing home residents), and to assess the extent to which a proxy/helper participated.

Screening for cognitive impairment. Researchers and policymakers should think carefully about arbitrary cut-offs which automatically exclude persons with mild or moderate cognitive impairment from studies. While not able to address all dimensions of a survey, cognitively impaired individuals may be able to respond to a subset of questions or to choose among fewer response choices. Some respondents can reliably answer one survey, but not another that may be more complex.

Traditionally, researchers depend on informal caregivers or program providers to ascertain whether an individual is able to participate in the survey process. For some groups of frail elders, objective assessment data on cognitive ability may be available as an independent screen for the survey process. For example, all nursing facility residents are assessed using the Minimum Data Set (MDS), a portion of which includes questions related to cognitive impairment. Use of the MDS cognitive score eliminates the need to separately screen as part of the survey process and/or to rely on the judgment of others regarding an individual's ability to participate in the survey. It may also allow researchers to adjust the threshold of cognitive impairment based on the complexity of the survey.

Fewer questions. Participants advocated that the number of questions on a survey be reduced and targeted to the primary purpose of the survey and the input of end-user stakeholders. Variations

within programs serving the frail elderly may be evaluated more effectively by the use of more focused surveys that are limited in scope.

Core questions. The concept of a “tiered” or modular approach to surveying was proposed, both as a way to reduce survey length and to facilitate comparisons across programs, states and over time. “Core” concepts could be part of all surveys; additional questions could be developed based on topical areas of relevance to a given population or program. “Core” concepts, as envisioned by participants, represented areas of universal interest, such as “beneficiaries should be treated with respect”.

Simpler questions. More can be done to reach persons with limited cognitive impairments through standard surveys. Reducing the total length and complexity of a survey, using terms familiar to frail elders, and employing dichotomous (yes/no) response scales not only would expand the universe of frail elders that can respond but makes response easier for all frail elders. Rigorous pretesting strategies such as cognitive interviews can help to detect comprehension and judgment problems.

Non-traditional survey approaches. Traditional survey research relies on strict adherence to standardized survey protocols that constrain interviewers from rephrasing or explaining survey questions. While these methods increase inter-rater reliability in survey administration in the strict research sense, they restrict the ability of respondents to answer questions fully and accurately. Focus on reliability and internal consistency of responses also add to the number and usually the complexity of questions – factors that work against frail elders in general and those with cognitive impairments in particular. Open-ended questions and probes (e.g., “tell me more”), while difficult to code without subjective interpretation, allow persons to respond to questions in their own words. Persons with cognitive impairments can express preferences and feelings about services. The problem is one of measurement. A different construct is needed to measure the experience of those who cannot respond to conventional surveys. For example, observations regarding levels of discomfort (e.g., pain, cries, level of agitation) may be easier to assess than levels of satisfaction. The field of pain assessment offers useful strategies for expanding the ability of individuals to ask and respond to questions in meaningful ways.

Use of Proxies. No one can actually speak for another without introducing bias. Studies of nursing home residents, their staff and family members show low correlation. No consistent patterns are found in how staff and family respond compared to resident response. Proxies may be appropriate to report objective data, such as the age or functional status of a beneficiary. Although there may be differences even in these areas, greater agreement is likely. When important to the evaluation or performance of a program, perspectives of staff, caregivers, and family members may be obtained through separate surveys on matters relating to their roles in a given service delivery system.

Role of interviewers. A survey interviewer is the intermediary for a face-to-face survey and as such plays an important role in establishing effective communication with a respondent. Strong interpersonal skills and knowledge of the constraints under which frail elders labor in responding to surveys, as well as technical training on the substance of the survey, are prerequisites. Early in the testing phase of surveys, researchers should solicit feedback from interviewers regarding areas where the survey can be revised to improve comprehension, consistency of administration, and response rates.

Rapport and familiarity with respondent. Responses may vary when a subject establishes rapport with an interviewer. An example was cited of nursing home residents whose positive responses to survey questions were later contradicted during more casual conversations with interviewers. In a social context, residents felt more at ease in discussing details that suggested problems with their care. There is no substitute for this rapport factor but due to its time and resource requirements, it is frequently not built into survey research.

Response bias may be aggravated when staff or caregivers are called upon to introduce survey interviewers. Although this practice is intended to ease transitions, it also can confuse the boundaries of a survey and raise issues of confidentiality for the beneficiary.

Scheduling and pacing surveys. Many complications arise when trying to accommodate the fatigue of frail elders during the survey process. Interviews need to be scheduled during periods of peak alertness and the participation of caregivers, facility administrators and family members to work around other scheduled events. Surveys may need to stop and resume based on a respondent's stamina. The costs of tailoring the survey process to each individual can be prohibitive if respondents are not physically clustered in a single location such as a nursing facility.

Response metrics. Dichotomous response categories (yes/no) are easier to understand than other more complex response scales (e.g., Likert scale) that require the respondent to rank their experience (e.g., 0 to 10; or "always", "sometimes", "usually", "never"). Some surveys combine the two approaches by first asking a specific yes or no question, and then asking how the respondent would describe the extent of their agreement or disagreement. For example, the Home Care Satisfaction Measure uses responses from "yes, definitely, "yes, I think so" to "no, definitely not." This combination method may produce different results than the true Likert scale, and may produce different responses than a self-administered survey where all choices are shown at once. On the other hand, the opportunity to include those with some impairment (who perform better on yes/no type items) may outweigh measurement concerns.

Conclusions

The Symposium offered an opportunity for researchers to provide policymakers with firsthand knowledge about approaches and challenges to surveying frail elders. While much of the focus during the two-day meeting was on technical considerations for more effective survey design and administration, policymakers repeatedly returned to the practical implications of implementing many of the proposed strategies. Several major concerns consistently re-surfaced.

- **Need to clarify the purpose of the survey.** Policymakers must be clear and make certain that those who are administering the survey are clear about the primary purpose of the survey. This will ensure that the survey instrument is designed to gather the data that policymakers are seeking and reduce inappropriate use of survey data.
- **Use of other data sources.** States should limit survey questions to those that cannot be answered through other data sources. This helps to reduce survey length and beneficiary frustration in providing similar information multiple times.

- **Education and training.** States have limited knowledge and experience in surveying frail elders and are largely dependent on vendors to conduct this work. Many of the proposals advocate that surveys be tailored to the specifics of state programs, populations and resource capacity. This is an enormous developmental effort and requires advice and direction from the geriatric research community in the form of working tools or templates for survey design and guidance for the selection of knowledgeable vendors.
- **Resources.** The compelling advantages of face-to-face surveys for this population are offset by the staggering costs for doing so across institutional, home and community settings. More incremental approaches may be necessary to design and test strategies among subsets of this population.
- **Relationship to other surveys.** HCFA requires the CAHPS survey of all Medicare risk contractors and is currently developing a separate CAHPS module for nursing facility residents. Some states, as a condition of waiver approval, are required to use CAHPS and/or to participate in independent evaluations that include a survey component. States as well may conduct surveys of HCBS waiver enrollees and other state-sponsored services for frail elders. Given that frail elders are frequently dually eligible for Medicare and Medicaid, it is important for federal and state policymakers to coordinate survey efforts and eliminate potential duplication.

It was agreed that much work remains to be done. It was also agreed that much already has been learned that can be put into practice. Building awareness of the issues faced when surveying frail elders is the first step to assuring that their voices are heard. Participants also understood that the research and developmental work suggested throughout the Symposium required expertise and resources beyond what most states could individually contribute. The continued engagement of the research community was recommended to assist in these efforts at the state, regional and national levels.

Excerpt from:

Limitations in Understanding of Health Care and Satisfaction Terminology by Frail, Older Adults:
Results from a Consumer Survey Among Participants of the Connecticut Home Care for Elders
Program

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Literature Review

Health care policies that are developed using erroneous or incomplete survey-based information are likely to be inappropriate or ineffectual. Data that reflect misinterpretations or misunderstandings of survey questions can accordingly directly or indirectly affect patient and organizational outcomes, practice patterns, and health care delivery, including quality and costs of care. To date, a large body of work has been published examining the role of cognition and communication on the survey research process. More specifically, survey methodologists have created a field devoted to understanding self-reports and to improving the quality of data collection. However, despite the extensive literature in this area, only a smattering of chapters and articles have addressed issues unique to the older population, beyond basic cognitive decline.

The cursory review by many research articles includes a discussion of response rates, face and content validity, the use of preexisting survey instruments, and response distribution. However, little emphasis is focused on determining whether the respondent² understood the question the way in which the researcher had intended. In particular, Schwarz (1999) raises two key questions:

- 1) Is the attitude object, or the behavior that the respondent identifies as the referent of the question the one that the researcher intended?
- 2) Does the respondent's understanding tap the same facet of the issue and the same evaluative dimension?

Researchers are in the infancy stages of exploring the impact of membership in an older cohort on survey responses, including not only how older respondents interpret questions and provide answers, but also why those answers are provided (Rodgers & Herzog, 1992). Recognizing the importance of including older individuals in survey methodology, researchers have begun to utilize different survey techniques in an effort to accurately capture the experiences and perceptions of an older population (Jobe et al., 1996; Forbes & Neufeld, 1997). Cognitive interviewing techniques, which emphasize understanding the thought processes of the respondent in forming an answer, has been particularly helpful when interviewing community living older adults, age 65 and older (Keller et al., 1993; Jobe et al., 1996; Forbes & Neufeld, 1997).

1. Answering a Question

The process of answering a question is a multi-level cognitive process. Respondents mentally progress through four cognitive stages before arriving at an answer to a question: comprehension; retrieval; estimation and judgment; and response (Tourangeau, 1984; Strack & Martin, 1987; Jobe & Mingay, 1989). Comprehension, or understanding the question, requires that the respondent interprets the question and understand its meaning. Understanding the question and what it refers to involves determining first the literal, and then the pragmatic meaning of the question. While literal comprehension involves identification of the words and their literal meaning, understanding the pragmatic meaning requires placing the question in context to determine the intended meaning of the question (Sudman et al., 1996; Schwarz, 1999).

² Throughout this brief the words "respondent" and "participant" will be used interchangeably to describe the home care clients who were interviewed.

Although the meaning may seem straightforward and unambiguous to the researcher, most questions require inferences to be drawn in order to answer them appropriately (Schwarz, 1999). Clues such as the stated purpose of the questionnaire, the researcher's affiliation, the response alternatives provided by the researcher, and the content of adjacent questions are used by the respondent to help interpret the intended meaning of the question (Tourangeau, 1984; Sudman et al., 1996; Schwarz, 1999). Even the particular groupings of questions in the survey can help the respondent deduce the intended meaning of the question, as the grouped questions give the respondent a helpful context for interpreting their intended meaning (Tourangeau, 1984).

After interpreting the question, respondents must then retrieve the relevant information from memory (Tourangeau, 1984; Jobe & Mingay, 1989). While a previously formed opinion may be available to the respondent, it is more likely that the respondent will need to recall appropriate information from memory in order to directly compute a judgment (Sudman et al., 1996). This process may require respondents to remember specific behaviors, such as when recalling how many times they visited the doctor in the past six months.

As with comprehension of the question, the process of retrieving information from memory has inherent difficulties that may contribute to a biased or inaccurate response. For example, when recalling a certain behavior, it is usually difficult to remember specific instances of repetitive events, such as physician visits (Linton, 1982; Loftus et al., 1992). Instead, similar instances run together, as the particulars are forgotten but the general pattern is retained (Tourangeau, 1984). Events that stand out, and are therefore easier to remember, are the ones that are different or abnormal in some way (Bower et al., 1979; Hastie & Kumar, 1979).

Another inherent difficulty associated with recalling items from memory is the incompleteness of the retrieval process. Respondents generally do not search their memories extensively when answering a survey question, but stop to compute their judgment when they have recalled what they consider to be enough information to formulate a sufficient answer (Sudman et al., 1996; Schwarz, 1999). Unless the respondent is very motivated or the issue is seen as personally relevant, only information that is readily accessible is used to compute the answer (Sudman et al., 1996; Schwarz, 1999).

The next step in the cognitive process involves estimation and judgment to evaluate the retrieved information and compute a judgment (Tourangeau, 1984; Jobe & Mingay, 1989). Many questions require the respondent to summarize the information retrieved, compare different sets of information, or draw inferences from available information before determining an answer. For example, when reporting on specific behaviors, the respondent must not only determine that the recalled behavior occurred during the specified period, but must also ascertain that the behavior or opinion is representative of their perceived experience or views (Sudman et al., 1996).

Estimation strategies are frequently used when evaluating multiple behaviors or events, as respondents form an estimation from the general knowledge easily accessible in their memory, rather than examining each separate episode of behavior (Jobe & Mingay, 1989; Loftus et al., 1992; Sudman et al., 1996). This may have some advantages, such as when reporting the frequency of an event. For example, in a study of 373 HMO members ranging in age from 14 to 82 (mean age 42.5), respondents were only able to remember 39% of their actual visits when asked to report each doctor visit they specifically remembered over the past year. However, when asked to provide an estimate of the total number of doctor visits over past year, without having to recall each separate visit,

respondents provided a more accurate estimate, reporting 87% of the actual total number of visits (Loftus et al., 1992). This corroborates previous research that people have a general idea of how frequently events have occurred in their lives, even if they cannot specifically remember each separate instance (Hasher & Zacks, 1984).

Once a judgment or estimation has been computed, the respondent must then choose a response (Tourangeau, 1984; Jobe & Mingay, 1989). If response categories are provided, the respondent must also format their answer to fit the available response options (Sudman et al., 1996; Schwarz, 1999). Thus the response alternatives themselves may have considerable impact on the answer given (Schwarz, 1999). In a study involving dietary intake in retired people age 50 to 70, cognitive probes found that respondents were eating cereal more often than they indicated, but had not checked the response option “breakfast foods” because they were also eating cereal at other times of the day (Jobe et al., 1996). The respondent may also choose to edit their responses before reporting them, due to reasons such as self-presentation or social desirability (Jobe & Mingay, 1989; Sudman et al., 1996; Schwarz, 1999). These issues will be discussed in more detail below.

2. Influence of Aging

Previous studies have indicated that some cognitive differences do exist between younger and older (65 and over) populations, and that the survey responses of older adults are affected by these differences (Keller et al., 1993; Park et al., 1994; Jobe et al., 1996). Several factors may contribute to the cognitive difficulties experienced by older adults. One factor may be the difference in overall education levels between the two adult populations, with smaller proportions of highly educated people being found in older populations (Herzog & Dielman, 1985). Another contributing factor may be that older adults have less recent experience with cognitive tasks such as answering a survey (Jobe et al., 1996). Difficulties in responding to survey questions may also result from memory problems, including problems with both storing and retrieving information which seem to worsen with increasing age (Craik, 1977; Loftus, 1982; Colsher & Wallace, 1989; Park et al., 1994; Jobe et al., 1996; Carlesimo et al., 1998).

Comprehension difficulties of older respondents reported in health related research include greater inaccuracies, such as when reporting hospitalizations and doctor visits or when recalling information (Anderson, 1979; Park et al., 1994). This age-related cognition finding is not universal, as Herzog and Dielman (1985) found no age bias when reporting factual information. Loftus and colleagues (1992) also found no age-related recall bias, as age was not significantly related to completeness or accuracy of recall in their study of adults age 14 to 82. Jobe and Mingay (1989) reported a tendency of older participants to respond with narratives and a subsequent resistance to translate their estimated answers into the categories provided. Other difficulties for older respondents reported by Jobe and colleagues (1996) include problems with aggregation, difficulty estimating, and frequent editing of responses.

Difficulties in question interpretation have also been noted in previous research (Keller et al., 1993; Jobe et al., 1996; Park et al., 1994), although again this is not a universal finding (Rebok et al., 1988; Szuchman & Erber, 1990; Adams et al., 1997). Park and colleagues (1994) reported that older adults had a greater difficulty interpreting the inferred meaning of the question, although the majority of normal older adults were able to successfully interpret the literal meaning. However, a comparison of younger and older adults revealed no significant difference in their ability to grasp which was inferred or implied (Rebok et al., 1988). A tendency was also reported for older respondents to

interpret questions regarding functional status, a concept which may seem very straightforward to many researchers, as conditional on circumstances, or to seemingly deny their functional limitations (Keller et al., 1993; Jobe et al., 1996). For example, in a study of perceived functional status among community living older adults, 39% agreed that using a cane to walk across a room was an example of doing something by yourself and not using aids, and when asked about examples of help from another person, 47% stated that sitting on a special seat in the bath or shower was an example of receiving help from another person (Keller et al., 1993).

3. Socially Desirable Response Set Bias

Socially desirable response set (SDRS) describes the tendency of respondents to give answers consistent with the prevailing social norms rather than accurate personal responses (Forbes & Neufeld, 1997). While respondents are generally motivated to be “good respondents” and give complete and accurate information, respondents may also be reluctant to give answers that they believe to be socially undesirable (Sudman & Bradburn, 1982; Sudman et al., 1996). Although a possible factor in all social research, this issue is especially relevant for satisfaction research, where the respondent is asked to evaluate and offer their appraisal or critique of an issue.

This effect may be particularly strong for older respondents, as older adults often score higher on social desirability response scales (Campbell et al., 1976; Gove & Geerken, 1977). The effect may also be compounded by the greater tendency for older adults to conform more readily to group pressure (Klein, 1972; Klein & Birren, 1972). Respondents with a lower socioeconomic status also exhibit a greater SDRS bias than higher SES respondents (Ross & Mirowsky, 1984; Ross et al., 1995). SDRS bias has been recognized as an important methodological issue when surveying client satisfaction in elderly clients receiving home care services, along with other potential response biases such as acquiescent response sets and fear of reprisal (Forbes & Neufeld, 1997).

Questions with a personal referent (“does your doctor”) rather than a general referent (“do doctors”) may also produce a stronger SDRS bias (Nehring & Geach, 1973; Hays & Ware, 1986). For example, while it was difficult for respondents to report negative experiences of their care, it was somewhat easier for them to comment on perceived deficiencies in their roommate’s medical care (Nehring & Geach, 1973). This effect was echoed by the positive personal referent SDRS bias found by Hays and Ware (1986). In this study, respondents consistently rated their medical care more positively than the care received by others, leading these researchers to caution that items using a personal referent may be consistently biased upward (Hays & Ware, 1986). This may be of special concern for satisfaction surveys written with personal referent items.

Related response biases which may also influence replies in a similar manner include self-presentation, fear of reprisal, and medical paternalism. Respondents are motivated to appear to be “good people” and want the interviewer to view them positively (Sudman & Bradburn, 1982; Bickart & Felcher, 1996). This need for positive self-presentation can touch on a wide variety of concerns, including embarrassment over one’s true behavior, concerns over appearing abnormal or deviant, fear of appearing unintelligent or unknowledgeable, or wanting to impress the interviewer (Pearson et al., 1992). Concerns over self-presentation may influence a respondent’s judgments or cause them to edit or change their private response before communicating a response to the interviewer (Bickart & Felcher, 1996; Schwarz, 1999).

Another facet of SDRS bias is refusing to report any negative opinions for fear of retribution or reprisal. This bias becomes stronger if there is a perception that the interviewer is somehow connected with the institution or organization which is being evaluated or if the interviewer is a service provider (Nehring & Geach, 1973; Forbes & Neufeld, 1997). In one study on health care satisfaction, respondent candor was more likely if the interviewer was not associated with a health care agency (Fitzpatrick, 1984). Distrust of the interviewer, or doubt by the respondent that their confidentiality will be respected, also creates a greater tendency in respondents to deliberately underreport negative experiences (Nehring & Geach, 1973; Forbes & Neufeld, 1997).

Fear of reprisal has been reported in medical service satisfaction surveys with both hospital patients and with elderly home-care clients (Nehring & Geach, 1973; Forbes & Neufeld, 1997). For the elderly home care clients, fear of losing their services was a particular concern, which created difficulties for the researchers to fully capture their home-care experience (Forbes & Neufeld, 1997). As with the effects of self-presentation, emphasizing anonymity and confidentiality during the survey process may help alleviate this bias (Sudman & Bradburn, 1982).

The influence of medical paternalism, the perception that the doctor knows best and should not be questioned, can be considered a type of SDRS bias. In the traditional, paternalistic medical model, the doctor has the ultimate authority and is expected to make decisions on behalf of the patient, while the patient complies with the decision (Gallagher, 1998; Benbassat et al., 1998). Although widely practiced years ago, medical paternalism is usually seen as outdated, as a more mutual doctor-patient relationship is evolving in medical care (Weiss, 1985; Gallagher, 1998). However, a review of the literature indicates that this more active patient role has not been fully adopted, and medical paternalism is still particularly strong for certain subsets of patients, especially those patients who are older, have increased severity of sickness, or have a lower socioeconomic status (Williams, 1994; Benbassat et al., 1998; Stevenson et al., 2000).

When evaluating patient satisfaction among an older, frailer population, it is hypothesized that a tendency to delegate their medical decision making autonomy to their doctors might contribute to an increased SDRS response bias, as these respondents may be more unwilling to voice any concerns they might have over their care. Furthermore, as a frail, elderly population, the lives of these respondents, more than other older adults, very much depends on the care and medications they receive from their doctors and other healthcare workers. This dependency would be expected to increase the tendencies towards SRDS response bias as well.

4. Acquiescent Response Set Bias

Acquiescent response set or bias (ARS) describes the tendency to agree with statements of opinion regardless of their content (Ware, 1978). With respect to instruments measuring levels of satisfaction, agreement with positively worded items results in reportedly higher levels of satisfaction, while agreement with negatively worded items results in lower levels of satisfaction (Ross, et al., 1995).

Previous research has found substantial ARS bias in patient satisfaction measurement surveys (Ware, 1978; MacKeigan & Larson, 1989; Ross et al., 1995). When measuring patient satisfaction in an older, predominantly lower income, and more chronically ill population, Ross and colleagues (1995) found a substantial ARS bias, occurring in 66% of their sample. Highly acquiescent respondents were significantly older, less well-educated, and in poorer health than nonacquiescent respondents

(Ross et al., 1995). This corroborates previous research which found that ARS bias is significantly associated with lower socioeconomic status, including both lower education levels or less income (Ware et al., 1976; Ware, 1978). This study by Ross and colleagues (1995) appears to be the first one that measured age as an influencing factor in ARS bias, finding an association with increased age. Ross and colleagues (1995) postulated that in their older, lower SES, and more ill population, the higher levels of ARS may also reflect response difficulties due to limited education, fatigue, communication problems, or impaired cognitive functioning.

5. Impact of Health

Another set of variables one must consider when surveying older adults is the impact of their physical health on the survey process. Sensory deficits frequently experienced as people age include hearing and/or vision loss (Havlik, 1986; Herzog & Rodgers, 1988; Williams, 1995). Both can inhibit communication between the respondent and the interviewer or research facility (Jobe et al., 1996). Large print surveys or written communications cannot always compensate for poor eyesight, and loss of hearing can make telephone interviews impossible and in-person interviews extremely difficult (Rodgers & Herzog, 1987).

Other detrimental effects of poor physical health include greater fatigue and increased pain and discomfort, both of which increase the likelihood that the interview will not be completed or will not be completed accurately (Ross et al., 1995; Jobe et al., 1996). Frailer individuals, such as elderly home care clients, may also need various forms of personal and medical assistance, and the interruptions caused by these activities or the arrival of the respondent's home health care workers can create difficulties for completing the interview (Nehring & Geach, 1973; Forbes, 1996). These and other factors may contribute to the lower response rates for adults age 65 and older, as response rates decline linearly with increasing age (Herzog & Rodgers, 1988).

6. Health Literacy

Illiteracy, the inability to perform the basic reading skills necessary to fully function in society, affects 44% of adults in the United States age 65 and over (Kirsch et al., 1993). Inadequate health literacy may be even more pervasive. Health literacy refers to the ability to read and understand the information and instructions necessary to function effectively in health care settings (Proceedings: Promoting Health Literacy, 1998). This would include the ability to read and understand discharge information, medication instructions, appointment cards, medical education brochures, and other essential health-related materials. Although these health-related materials may be written at a similar level of complexity as other non-medical materials readily understood by the patient, their unfamiliar vocabulary and content may make them even more difficult to read and understand (Ad Hoc Committee, 1999).

Estimations of the prevalence of health illiteracy in the older United States population vary. One study estimated an overall prevalence of 34% in English-speaking adults age 65 or older (Gazmararian et al., 1999), while another reported that 81% of English-speaking patients age 60 or older had inadequate health literacy (Williams et al., 1995). Low health literacy can affect not only a patient's knowledge of his/her health conditions, but can also negatively affect a patient's self-care such as adherence to treatment plans and self-management skills (Williams et al., 1998; Parikh et al., 1996). In one recent study involving patients at two public hospitals, 42% of patients could not understand directions for taking medicine on an empty stomach, and 26% were unable to understand appointment slip information (Williams et al., 1995). In another study involving new

Medicare enrollees in a managed care organization, almost half (46%) of enrollees did not understand the Medicaid rights and responsibilities reading comprehension passage (Gazmararian et al., 1999). Furthermore, embarrassment and shame may prevent these patients from asking for the help they need to understand this basic medical information (Parikh et al., 1996; Baker et al., 1996).

Greater health illiteracy is correlated with less education (Parikh et al., 1996; Gazmararian et al., 1999), although notable proportions of individuals with at least a high school education have been found to have inadequate or marginal health literacy as well. One study of Medicare enrollees found that 27% of older respondents with at least a high school education had inadequate health literacy (Gazmararian et al., 1999), while another found that one fifth of adult high school graduates had inadequate or marginal health literacy (Williams et al., 1995). In addition to years of education, inadequate health literacy is correlated with worse health (Weiss et al., 1992; Williams et al., 1995); having at least one target chronic condition (Gazmararian et al., 1999); increased risk of hospitalization (Baker et al., 1998); and increasing age (Williams et al., 1995; Parikh et al., 1996; Gazmararian et al., 1999). Given the greater proportion of older adults with a lower educational background (Herzog & Dielman, 1985) and higher prevalence of ill health and chronic conditions found in the elderly population (Williams, 1995; Jobe et al., 1996), the greater prevalence of inadequate health literacy in this cohort is not surprising. In the largest study to date involving older managed care enrollees, Gazmararian and colleagues (1999) conclude that elderly managed care enrollees may not have adequate health literacy skills to navigate and function in the current health care environment, and that this may impair their ability to care for their medical problems.

7. Satisfaction

Although surveys on patient and client satisfaction with medical care are increasingly used as indicators of quality of care, the results must be viewed with awareness of the common methodological issues common to much satisfaction research (Hays & Ware, 1986; Cleary & McNeil, 1988; Campen et al., 1995; Ross et al., 1995). The accuracy and reliability of many of these instruments has not been established, as most patient satisfaction surveys have not been validated (Carey & Seibert, 1993; Campen et al., 1995). Measurement of satisfaction is difficult due to response biases such as positive or negative wording of items, socially desirable response set bias, acquiescent response set bias, and fear of reprisal (Nehring & Geach, 1973; Ware, 1978; Hays & Ware, 1986; MacKeigan & Larson, 1989; Ross et al., 1995; Forbes & Neufeld, 1997).

Of equal concern when measuring patient satisfaction is the validity of the concept itself (Cleary & McNeil, 1988; Williams, 1994). Patient satisfaction is a multidimensional issue which is not easily summated into a simple measurement of care (Fitzpatrick & Hopkins, 1983; Williams, 1994; Kirsner & Federman, 1997; Sitzia & Wood, 1997). Meaningfully determining the experience and attitudes of patients requires the researcher to examine the many aspects of care, including the patient's own evaluations and beliefs (Williams, 1994; Sitzia & Wood, 1997).

These measurement difficulties may contribute to the biased satisfaction findings found repeatedly throughout the literature. These include the tendency of older patients to report high levels of satisfaction, especially when compared with younger patients (Locker & Dunt, 1978; Ross et al., 1995; Lee & Kasper, 1998), and the greater levels of satisfaction often reported by women when compared with men (Shortell et al., 1977). Lower socioeconomic status has also been correlated with greater levels of satisfaction when rating medical care (Ware et al., 1976), as well as greater

socially desirable response set and acquiescent response set bias (Ware, 1978; Ross & Mirowsky, 1984; Ross et al., 1995; Forbes & Neufeld, 1997).

Accurate evaluation of patient satisfaction in older, frailer patients may be particularly difficult due to the potential cumulative effect of several response biases (Ross et al., 1995; Forbes & Neufeld, 1997). Previous research has also revealed a low internal consistency of satisfaction measures in an earlier population of home care clients (McCusker, 1984). Different research methods, such as the use of probing, vignettes, and other cognitive interviewing techniques, have been successfully modified and used to help offset these effects in older adults (Jobe et al., 1996; Sudman et al., 1996; Forbes & Neufeld, 1997).

8. Cognitive Interviewing Techniques

Cognitive interviewing techniques are often used to study a participant's response process, in addition to identifying errors that may be introduced during the interview. The primary goal of this technique is to construct, formulate, and ask better survey questions. In addition, these approaches can determine whether question wording communicates the objective of the question, can identify problems related to redundancy or awkward wording, and can provide insight related to response error.

Forsyth & Lessler (1991) discuss a broad array of cognitive testing techniques, but the one with the broadest appeal to social scientists is the think-aloud technique. Interviews are conducted one-on-one by an interviewer with a research participant from the target population. Respondents are asked to think out loud or verbalize their thoughts as they attempt to understand the question, retrieve relevant information from memory, and formulate their response. Interviewers are trained to use scripted probes to clarify ambiguous thoughts and statements.

Think-alouds can be retrospective (probe questions are asked at the end of the interview) or concurrent (probe questions are asked immediately after the respondent answers the question). The sessions are usually audio recorded to minimize note taking during the interview. The purpose of think-alouds is to identify comprehension, misperception, interpretation, and recall problems (Demaio & Rothgeb, 1996). A major goal is to gain an understanding of the cognitive processes that respondents use to formulate their answers.

Within the think-aloud interview, probing questions and paraphrasing are often used to gain further understanding of how the respondent derived their response. With this method, follow-up questions are asked after the respondent answers a question or after a series of related questions. Comprehension probes include asking respondents to paraphrase a key phrase, define a term used in a question, elaborate on an aspect of their response, rate the clarity of a phrase or concept, and identify words or phrases that are difficult to understand. The purpose of these probes is to identify terms or concepts that respondents do not understand or that they interpret differently than intended and to determine if the respondent missed important words or qualifiers that are part of the question, such as "in the past six months" (Ericsson & Simon, 1993). Finally, follow-up probes are also used to evaluate the adequacy of given response categories. If respondents repeatedly use different words or choices than those offered by the question, further exploration is warranted.

Cognitive survey techniques are especially important when working with an older population. Several studies suggest that the cognitive abilities of older people (age 65 and older) are different

than those of younger individuals, which may affect the quality of survey responses (Keller et al., 1993; Park et al., 1994; Jobe et al., 1996). A study conducted by Jobe and Mingay (1989) set out to determine whether think-aloud interviews with extensive probing could be used to investigate the cognitive processing of survey questions among older respondents. Four primary findings were reported. First, probe questions were successful in discovering comprehension problems with the questions, especially in instances when thinking aloud tended not to occur. For example, respondents reported that they could perform a particular physical activity with no difficulty, however, probing revealed that they had not even attempted it for several years. Second, many older respondents had difficulty recalling dates from the distant past. In addition, the specific wording of the date question yielded varied responses, i.e., “what was the month and year” versus “how long ago.” Third, when asking information pertaining to estimation and judgement, older respondents consistently responded with narrative answers and were resistant to providing category answers of the type usually required on traditional surveys. Finally, probe questions were successful in determining when respondents had edited their answers. For example, many of the respondents compensated for their functional limitations and denied the limitations when questioned. When probed in greater detail, however, the limitations and compensation became obvious.

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Three Initiatives to Survey Frail Elders:

- I. A Pilot Study to Test a Modified Version of the Consumer Assessment of Health Plans (CAHPS)
- II. The 2000 MSHO Nursing Home Beneficiary Survey
- III. Consumer Satisfaction Measurement Tool Project, National PACE Association

I. A Pilot Study to Test a Modified Version of the Consumer Assessment of Health Plans (CAHPS)

In 1999, the Braceland Center for Mental Health and Aging, under contract with the Connecticut Department of Social Services, conducted a pilot study of a modified version of the CAHPS survey instrument to a group of active participants of the Connecticut Home Care Program for elders, a 1915(b) waiver program. Persons with known cognitive impairments and non-English speaking individuals were systematically eliminated from the sample.

The survey instrument was based on the Medicare and Medicaid managed care modules of the CAHPS. In selecting questions for inclusion in the instrument, focus was on high priority areas across the New England States with special emphasis given to care coordination. Language of some of the questions was modified to simplify reading level. As well, questions were combined to reduce the number of skip patterns. To better assess question comprehension, recall and estimation, scripted probe questions were developed similar to those used by the CAHPS project teams at Harvard, RAND and RTI.

Methods of survey administration included phone, mail and in-person interviews. The final mail version of the survey instrument included 48 items. The phone and in-person interviews used the 48-item core survey with an additional 67 cognitive/probe items. A total of 209 surveys were completed, including phone, mail, mail with phone follow-up to non-respondents, and in-person.

Telephone survey results identified the following problems:

Hearing: Approximately 65-70% of respondents had moderate to advanced hearing impairment that impeded the accurate collection of survey data. Hearing problems were confounded by the use of words unfamiliar to the respondent and/or cognitive impairments which made it difficult to sort out problems related to hearing versus comprehension.

Comprehension: Most respondents had difficulty comprehending at least one survey question as indicated by contradictory or nonsensical responses. Reading level, complex sentence structures and the use of unfamiliar words exacerbated comprehension problems.

Scales: Likert scales, requiring respondents to rate a response from one to ten, proved particularly difficult for many respondents to understand over the phone.

Estimation: Estimating time intervals and the number of times a particular event occurred was hard for some respondents.

Problems with specific survey questions: Questions that included examples, were too long, or included references unrelated to how a respondent describes a situation or person were confusing to respondents.

Response bias: Respondents tended to answer in the affirmative to questions regarding their relationship with their doctors. Respondents saw negative responses as potentially reflecting poorly on themselves or out of fear or anxiety about losing benefits.

Barriers to survey administration: Fatigue, physical impairments, and competing demands greatly affected the ability of this frail population to complete the questionnaire. Adult caregivers also acted on behalf of respondents by limiting access to phone or in-person interviews.

Survey results are available through the New England States Consortium.

II. The 2000 MSHO Nursing Home Beneficiary Survey

The purpose of this survey was to conduct an independent assessment of beneficiary satisfaction with the Minnesota Senior Health Options (MSHO) program, a demonstration that integrates Medicare and Medicaid funding and acute and long term care service delivery for dually eligible seniors. This survey was a follow-up to one developed and administered by the University of Minnesota in 1998 at which time findings from face-to-face interviews with MSHO enrollees living in the community and nursing home were compared to participants of the State's Prepaid Medical Assistance Program, a mandatory managed care program that includes seniors. For the 2000 MSHO survey, modifications were made to the 1998 survey and interviews were limited to MSHO and traditional Medicaid beneficiaries residing in a nursing home and their families. The State contracted with Minnesota Health Data Institute to modify and conduct the structured interview survey format.

The 2000 survey included 39 questions to assess satisfaction and experience with the health plan and health care, including advanced medical directives and health status and adaptive living skills.

Multiple response options were used in the instrument, such as yes/no; agree/disagree; poor → excellent; yes, definitely → no, definitely not; never, sometimes, usually, always; and big problem, little problem, no problem. A short mental health status questionnaire made up the first section of the questionnaire.

The following issues was raised in the course of administering this survey:

Use of Proxies: In the 1998 survey, family and staff proxies accounted for 79 percent of the completed beneficiary surveys. Decisions were made to allow no family or staff proxies in the 2000 beneficiary survey. Separate family surveys were administered whether or not the beneficiary was deemed capable of participating in face-to-face interviews.

Determining cognitive capacity: Several alternatives were reviewed for determining whether a beneficiary was capable of participating in an interview. After considering chart reviews and the use

of a mental health status questionnaire to screen a random sample of residents, it was decided that the nursing home administrator would make an initial determination on which residents within a random sample were capable of participating. A mental health status questionnaire was used to determine the eligibility of remaining participants.

Budget: In an effort to minimize costs, interviews began in nursing homes with 2 or more sample residents.

Logistics: Efforts were made to minimize the disruption in the nursing homes and to communicate with staff regarding any change in a resident's status that might affect the ability to participate in the survey.

Structure of Questions: In general, language was too advanced. Respondents were frustrated by repeated questions on the detailed processes of health plan and health care and offended about questions concerning personal habits. Questions with Yes/No response options were most successful. Requirements that interviewers not reword questions restricted data collection in some cases.

Length of Questionnaire: Interviews were too lengthy, causing fatigue and stress to respondents.

Copies of the 2000 Medical Assistance Health Plan Survey and findings are available through the Minnesota Department of Human Services.

III. Consumer Satisfaction Measurement Tool Project, National PACE Association

For the past four years, the National PACE Association has been working to develop and test standardized satisfaction measurement tools specifically for the PACE population. The purpose of the tools is to give frail elder PACE enrollees a voice to express their satisfaction with care and to help sites identify program strengths and weaknesses from their client's perspective. Randomly sampled participants were channeled into one of three groups: Group A - single interview design (self consent); Group B - multi-stage interview design with survey administration occurring as close as possible to the time that the service under evaluation was received (family consent, participant permission); or Group C - no interview. Group B was intended for persons with some level of cognitive impairment. To meet the needs of PACE's ethnically diverse populations, surveys are being simultaneously developed in English, Spanish and Chinese.

Cognitive and psychometric tests have been completed on both Group A and Group B survey instruments. A short series of screening questions were asked at the beginning of each interview to ascertain a respondent's cognitive skills to interpret survey questions, recall information and events, make judgements, and choose responses. The average length of the cognitive interviews (Group A only) was one hour and respondents were selected for their strong communication skills. The psychometric interviews were approximately 45 minutes in length for Group A and approximately 5 minutes for each Group B section.

The following is a summary of the lessons learned from preliminary testing.

Cognitive testing: Respondents performed better with closed rather than open-ended responses and experienced difficulties with specific frequency questions and skip patterns. Generally, respondents were challenged by the complex concepts of certain questions and had difficulty distinguishing different care providers.

Psychometric testing: A framework was developed to examine a service category across all dimensions (interpersonal process, technical quality, system adequacy) as well as sub-dimensions across all services (medical, therapy, aides, meals, transportation, home care, recreation, social work). Initial psychometric testing has highlighted several issues that may have implications for refinement of the instruments: variation in respondents' ability to distinguish service categories; difficulties in wording, length, and complexity of questions; "show cards" as a critical component in soliciting response; and response options that do not match the questions.

Logistics: Certain factors impeded the survey process: limited time during the day when respondents are available to be interviewed; respondent's ability to withstand the rigors of surveying; demands placed on site staff to facilitate transitions before and after survey process; and the length of the survey.

Future analyses will be used to determine tool reliability and validity and to test assumptions about subdimensions and redundancies in questions. A second round of psychometric testing is planned before the tools are revised and refined.