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Describing Target Audiences for Facility-Specific Quality Information Provided by Medicare

Final Report

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EXECUTIVE SUMMARY

Purpose: To describe primary and secondary target audiences for the public release of facility-specific quality information provided by the Centers for Medicare & Medicaid Services (CMS), focusing on audiences for data relating to *nursing homes* and *home health care agencies* (priority areas for CMS) and on those target audiences who might have an incentive to use quality information for advance planning.

Methodology: The project team conducted a selective review of research as well as focus group research with representatives from the following groups of consumers and intermediaries involved with Medicare beneficiaries and their caregivers "upstream" in the planning and decision process:

- Caregivers[1] and/or Medicare beneficiaries who have sought information or support regarding their own or their loved ones' future health care needs;
- General consumers who have demonstrated advanced planning for future needs; and
- Formal information intermediaries in the care and decision-making process who assist beneficiaries and caregivers in placement decisions.

A two-person study team conducted a total of 12 focus groups between July 10 and July 19, 2002, at three research sites: Camarillo, CA; Providence, RI; and Boston, MA.

Selective Research Review: Key findings from a review of 26 research reports and studies salient to this Subtask are summarized below.

<u>The challenge of older consumers</u>

- The present cohort of older Americans has limited awareness of variations in health care quality.
- Most people judge quality based on the individual characteristics of their caregivers, rather than objective measures of clinical quality.
- Most older consumers and their caregivers respond to crises, instead of planning ahead for dependent care.
- Most older Americans tend to defer to the judgment of clinicians, rather than seek out information to make their own independent health care decisions.

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[1] For the purposes of this research, the term "caregiver" is defined as any friend or family member who has responsibility for the care and well-being of a person on Medicare, or who actively helps them make decisions about their health care, whether or not they provide direct physical care. In this instance, the term does not include persons who provide care as part of their professional responsibilities.

- Older Americans depend on family and friends as guardians, caregivers, sources of information, and surrogate decision makers.

Family and other caregivers

- The most common informal caregiving relationship is that of the adult child of elderly parents, followed by spouses and other relatives.
- Demographic characteristics of caregivers generally mirror those of the general population.
- Caregiving covers a spectrum of activities, but consumers often equate the term with personal hands-on care.
- Most caregivers balance work and family life, in addition to caring for elders.
- Many caregivers find it difficult to obtain needed services, both for financial reasons and because of the "hassle factor" associated with finding out what they need to know.
- Most caregivers know how to arrange for nursing home care, but few understand about the scope of services that encompass home health care.

Barriers to change

- Most elders and their caregivers are reluctant to anticipate, much less plan for, future dependency or long-term care needs, even in the face of apparent disability or functional decline.
- Many individuals feel ill prepared for the placement decision, even though they have long known that the need for such a placement is looming on the immediate horizon.
- Older people and their family caregivers are generally unfamiliar with the range of available services for dependent elders, except for nursing home care.

Trajectories of decline and triggers to action

- Family caregivers may fail to plan ahead because they become accustomed to intermittent crises and assume that their loved one will continue to bounce back.
- Hospitalization following acute episodes of illness may provide opportunities for health care providers to intervene in the lives of elderly patients at earlier stages to maintain as much independence as possible and slow the process of decline.

Characteristics of advance planners

- Research on behaviors around facility placement provides little insight into the behaviors and motivations of those potential "early adopters" of quality information who *do* plan ahead.

Understanding and using quality measures

- Consumers find it difficult to relate to quality measures as indicators of how well a facility performs in providing care.
- Most people have little or no experience with nursing homes, home health care agencies and other health care providers and have trouble understanding what it means to make choices among these health care providers.
- Health care professionals express concern about the potentially deleterious effects of public reporting of quality information.

Qualitative Research Findings

Characteristics and behaviors of advance planners and likely early adopters of quality information

- **Those most actively engaged in advance planning for needs relating to aging are men and women upon whom the responsibility for caregiving has fallen in the past.** Beneficiaries and caregivers who were most clear-sighted in their approach to future care needs were those who had shouldered the burden of caregiving for elders in the past. Many had taken care of a parent or a parent-in-law and knew from experience what to expect. This experience went a long way towards overcoming the denial and resistance common among family caregivers. Although women had more often assumed a caregiving role in the past, men also fell into this category. Many experienced caregivers were also only or eldest children. Experience caring for others also made these individuals more likely to plan for their own future.
- **Advance planners in this category have first-hand experience trying to gather information on long-term care alternatives and understand the value of good information.** Participants who had taken care of aging relatives told of how time-consuming it had been to track down information about available resources and care alternatives and described it as a "full-time job." These individuals were far more knowledgeable than other consumers about available resources and sources of information, including information about quality.
- **Advance planning for needs related to long-term care and/or aging does not reflect a consumerist orientation, in general.** Advance planners were motivated by *experience*, not by consumerism, and few reported consumerist behavior in other aspects of their lives. Respondents also emphasized the difference between planning for long-term care and other major purchasing decisions: "Choosing a nursing home is not like choosing to buy a car."

- **Male heads-of-household accustomed to assuming the fiduciary responsibilities of the family may represent a distinct category of individuals motivated to plan ahead for needs relating to aging, regardless of prior caregiving experience.** Although prior experience was the most striking characteristic shared by the advance planners interviewed for this project, a small number of male heads-of-household from relatively affluent backgrounds who lacked such experience appeared to be motivated to plan ahead by a more traditional paternalistic sense of responsibility for the family's welfare. They were also more likely to be active consumers of comparative information, generally. In contrast to advance planners with prior caregiving experience, however, these individuals also appeared to keep their emotional distance from the planning process, even when they had aging relatives for whom they were responsible. Notwithstanding their emotional distance and even denial, these individuals appeared to be receptive to factual information and to offers of help that allow them to engage in information gathering in a detached and systematic way.[2]

- **Men may assume the role of planners and information gatherers in the family, while women may assume the role of caregivers.** Several respondents suggested that there is often a sort of division of labor in families, such that women deal with the physical care and emotional issues and men gather information (which allows them to maintain their emotional distance). However, the limitations of this research study did not permit exploring this issue in depth.

- **Advance planning for funerals is common, but it is not associated with advance planning for health care or other needs related to aging.** Planning for funerals did not necessarily indicate a realistic approach to dependency needs related to aging or a willingness to plan ahead for such contingencies. Death is recognized as inevitable, but the declining health and dependency that precede death are not topics most people care to think about.

- **Only children, especially those who are single, may also recognize the need to plan ahead, but they often do not know what to expect or where to turn for help.** Only children recognized that they were the ones who would have to take care of their parents if something were to happen, but they still found it difficult to think about what might happen and seemed reluctant to take action until serious problems arose. Most nevertheless thought that having information available early on would be useful.

Triggers to action

- **Witnessing problems relating to aging and functional decline in other persons' relatives can prompt concern about one's own aging relative or loved one.** Although all respondents commented on the difficulty of coming to terms with their parent's or spouse's functional decline and dependency, many exhibited *no* difficulty recognizing this trajectory

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[2] Because only a small number of respondents displayed these characteristics, the observations offered here are merely suggestive. Further research would be needed to probe whether such individuals may be true early adopters of quality information.

and its implications when it occurred in in-laws or other people's relatives. Hospital discharge planners also reported that adult children sometimes approached them for information about long-term care alternatives after visiting the ailing relatives of long-time friends. This suggests an inverse relationship between the level of intimacy between the caregiver and the aging relative and the ability to acknowledge functional decline and dependency.

- **Experienced caregivers and information intermediaries recognize triggers of concern further "upstream" in the trajectory of functional decline.** Respondents who were experienced caregivers as well as hospital discharge planners were more likely than others to recognize relatively subtle signs and signals that occurred long before there were serious signs of decline. These triggers of concern included moving to be close to adult children, loss of a car and/or driver's license, or an unwillingness to drive.

- **Most caregivers who lack prior experience delay taking action until there are more obvious signs of decline, further "downstream" in the process.** Most identified triggers of concern were associated with serious states of decline that virtually demanded intervention, including hospitalization, falls or serious mobility problems, leaving things burning on the stove, not eating, wandering, or not answering the telephone. When pressed, however, respondents reported noticing earlier signs of decline, such as deteriorating personal hygiene or housekeeping, to which they had failed to respond.

Perceived informational needs and concerns about quality

- **Most caregivers express the need, first, for information about available services and covered benefits. Concerns about quality arise once they have a clearer understanding of available alternatives.** Unless they have prior experience, most caregivers know very little about the kinds of services that are available, how much they cost, what is covered, and how they can be paid for. However, all caregivers agreed that quality was a major concern, once they understood their alternatives.

- **Most caregivers are interested in information relating to quality of care in nursing homes.** Concerns about the quality of care in nursing homes, fueled more often by media images of sensational cases rather than personal experience, often reinforce caregivers' natural resistance to considering nursing home placement for their parents or spouses. Yet these concerns have the effect of raising caregivers' awareness and may be a motivating factor about the importance of quality measures, creating an opportunity for communicating about variations in quality. Several respondents commented that they would be receptive to information about *good* nursing homes and acknowledged that inherent feelings of guilt about placing their parents would be minimized if they knew that such alternatives existed.

- **Caregivers' concerns about home health care services relate more to discomfort with "strangers in the house" than to concerns about quality.** In contrast to the concerns they expressed about nursing home care, caregivers raised few questions about the quality of home care services. Instead, what they mentioned most often was their discomfort with having strangers come into their parents' house, even when their parents seemed to enjoy the company. Surprisingly, this aversion to care in the home was sometimes stronger than the caregivers' aversion to assisted living or institutional long-term care.

- **Caregivers and intermediaries express interest in comparative facility-specific information about quality, but they are most likely to use it in conjunction with other, more subjective, sources of information.** Most respondents stressed that they made judgments about quality (and would continue to do so) based on other information – including cost, the recommendations of family, friends, and health professionals, and their own personal observations. Hospital social workers and discharge planners urged family members to visit nursing homes and make their own judgments, based on their personal observations.

- **Although hospital social workers and discharge planners are important sources of information to family caregivers, caregivers who are most actively engaged in advanced planning activities for their family members seek information from many, varied, and disparate sources.** Hospital-based intermediaries usually become involved after a family member has experienced a sentinel event in the trajectory of decline. Experienced caregivers therefore stressed the importance of gathering information in many different ways and from many different sources. No single source of information emerged from these experiences as most important or primary.

Implications for Communication Strategies: Messages and Channels

- **Target "early adopters" and advance planners as the primary caregiver audience.** This research suggests that *experienced caregivers* are a primary target audience for facility-specific quality information from Medicare who can be described as "advance planners." *Male heads-of-household* may also represent a distinct group of potential early-adopters of quality information, regardless of prior experience, although additional research would be needed to support this observation.

- **Frame messages to tap into the personal characteristics and motivations of target audiences.** *Experienced caregivers* appear to understand, from past experience, how difficult it is emotionally to deal with a loved one's functional decline and loss of independence. They may therefore be responsive to messages that acknowledge and tap into this emotional realism. *Male heads-of-household,* who lack past experience with caregiving, however, may *not* be emotionally prepared to deal with a loved one's functional decline. They may consequently *resist* messages based on an emotional appeal, but respond to those that appeal to their rational side and their sense of paternalism, allowing them to retain their emotional distance.

- **Target "contemplators"[3], such as only children or sole caregivers, as a secondary caregiver audience.** Only children or others who are the sole caregivers of elderly relatives may recognize that they will be responsible for taking care of aging relatives and making

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[3] The term "contemplator" refers to the stage model of behavior change discussed in greater detail in the Introduction to the full report.

decisions about home care or nursing home placement, but they may lack the emotional readiness or the motivation to take action until they are forced to do so. These individuals fall into the categories of *contemplators*, and, because they are more difficult to reach, may be regarded a secondary target audience among caregivers.

- **Frame messages to move "contemplators" to action by honing in on triggers, while acknowledging their emotional resistance.** The challenge in motivating *contemplators* to take action lies in getting them to recognize potential needs before they reach the crisis stage, and to recognize that planning ahead for such needs does not constitute a betrayal of their loved ones. They may be responsive to messages that acknowledge their emotional resistance but focus on "upstream" signs or triggers that advance planners have identified, stressing the advantages of planning ahead.

- **Target hospital social workers, physicians and discharge planners as a primary intermediary audience.** Hospital social workers and discharge planners are consistently identified by caregivers as playing an important role in the decision-making process and should therefore be considered the primary target audience among information intermediaries.

- **Frame messages to encourage intermediaries to engage in anticipatory guidance with family caregivers, focusing on "upstream" issues.** Experienced hospital social workers and discharge planners are in an excellent position to provide anticipatory guidance to family members. However, the demands of their jobs may be such that they focus more often on the immediate need to arrange post-hospital care rather than on longer-term care considerations. The challenges, then, are to build on their sense of professionalism to define their roles in larger terms and to provide them with easy-to-use tools, so as to minimize the additional burden that this new role would entail.

- **Disseminate information through a variety of channels in the local community, to reach family caregivers and raise their awareness before they are in crisis.** Caregivers reported spending a great deal of time sitting and waiting while they accompanied their family members to various appointments and suggested that they would be likely to notice information relating to caring for aging relatives at those times. Doctors' offices, emergency room waiting rooms, and pharmacies were mentioned most often, along with libraries, post offices and other community locations.

- **Acknowledge and build on concerns about the care provided in nursing homes to promote interest in quality.** Concerns about quality of care in nursing homes may provide a "hook" for prompting discussion and raising awareness about variations in quality performance and about measures of quality. Messages might acknowledge concerns, but offer positive solutions. Respondents commented that most of what they hear about nursing home quality is through the media and is usually "bad." However, they were open to hearing about "good" quality nursing home facilities from other reliable sources.

- **Frame messages around quality information within the context of larger issues related to planning.** Facility-specific quality information provided by Medicare cannot help consumers make meaningful decisions by itself. It should be promoted as *part of* a larger set of information about costs, benefits, and quality of services for the elderly, including those that are not covered by Medicare.

INTRODUCTION

The Centers for Medicare & Medicaid Services (CMS) is investing significantly in systems to collect and publicly report information about the quality of health care providers in order to help Medicare beneficiaries (and those who assist them) make better decisions regarding their care. To support these efforts, CMS has contracted with Ketchum Public Relations and its subcontractor, the Barents Group, a division of KPMG Consulting (now BearingPoint), to conduct a variety of research activities to inform reporting strategies for consumer use of this health quality data (Contract No. 500-01-0002, Task Order 5**,** "Research on Reporting Strategies for Informed Consumer Use of Health Care Quality Data"). The purpose of Subtask 4 under this Task Order, the subject of this report, is to describe primary and secondary target audiences for the public release of facility-specific quality information.

This current work builds on immediately prior work Barents conducted under CMS Contract No. 500-01-002, T.O. #2, TDL #3, "Synthesizing & Summarizing the Research," (as reported in Barents Group of KPMG Consulting, "Potential Audiences and Uses of Publicly Reported Quality Data," a Final Report submitted to CMS on November 2, 2001). This review of eleven CMS-sponsored studies related to public reporting of health care provider quality information (including nursing homes, hospitals, kidney dialysis facilities, and home health care providers), augmented by feedback from a Technical Expert Panel[4], revealed relatively consistent findings across all data sources. Specifically, the research review found that:

- Consumers and their family members have little time to review quality information, because they are often in crisis mode when faced with the prospect of selecting a facility.
- Consumers and caregivers are often overwhelmed by the amount of information that is available.
- Consumers express more interest in descriptive information about facilities and satisfaction measures than in measures relating to clinical quality and outcomes.
- Consumers need help understanding how to use the quality information that is currently available.

Based on these findings, the Report recommended strategies for enhancing the effectiveness of quality reporting efforts, including the following:

- Targeting family members who make decisions for aging relatives as a primary audience for quality information;
- Emphasizing the advantages of using quality information for advance planning by consumers and caregivers

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[4] Members of the Technical Expert Panel providing feedback on "Potential Audiences and Uses of Publicly Reported Quality Data" were Sherman Edwards, Judith Hibbard, Dale Shaller, Samantha Sheridan, Shoshanna Sofaer, and Robert Valdez.

- Identifying transition points in care that may be "teachable moments" for communicating about quality of care; and
- Targeting professional information intermediaries – including physicians, hospital discharge planners, ombudsmen, and health care counselors -- who have regular contact with consumers at critical transition points.

Given the consistency of findings regarding the challenges of promoting consumer use of comparative quality information, some researchers have suggested that the "transtheoretical" or "stage" model of behavior change (which has been successfully applied to a variety of difficult health behaviors, such as smoking cessation; the adoption of exercise regimens, and participation in mammography screening) might also apply to consumer use of quality data (Pro-Change Behavior Systems. "Application of the Transtheoretical Model to Informed Choice in the Medicare Population." Prepared for Center for Beneficiary Services, Health Care Financing Administration. May, 2000). In this context, the desired behavior would be the timely use of quality data to make informed choices among health care providers. According to the model, behavior change would proceed through a series of identifiable stages: *Precontemplation, Contemplation, Preparation, Action,* and *Maintenance*.

The processes of change, or interventions, that would move individuals from one stage to another would vary depending on which stage one was in. For individuals at early stages (*Precontemplation, Contemplation,* or *Preparation)* cognitive, affective, and evaluative processes of change would be appropriate. For those at later stages (*Preparation, Action,* and *Maintenance*) processes of social support, commitment, and behavior management (such as cues) would be in order. Since research suggests that most people in the target population (Medicare beneficiaries and their caregivers) are still in the *Precontemplation* stage of using quality information, anyone who actually uses information to plan in advance for their or their loved one's health care might be described as an "early adopter" of the targeted behavior. The challenge, then, is to identify opportunities, strategies, and interventions that might move others in the same direction.

Against this background, the research team and project officers at CMS agreed to focus research for Subtask 4 on the specific audiences and behaviors of interest – namely, the potential use of quality information for advance planning among family caregivers and information intermediaries, and the critical transition points and/or "teachable moments" for communicating about quality prior to crisis situations. In order to better meet CMS's needs and to better coordinate with the other subtasks subsumed under Task Order #5, the research team and the project officers at CMS also agreed for the purposes of this Subtask to focus *only* on audiences for data relating to *nursing homes and home health agencies*, two priority areas for CMS.

This report of research activities conducted under Subtask 4 presents (1) a brief review of recent relevant research identified by CMS project officers that was not covered in the earlier report, and (2) results from qualitative field research with individuals whom the research team and project officers identified as likely to shed light on the behaviors and characteristics of the "early adopters" described above.

The research team sought to address the following general questions:

- What are the characteristics of advance planners and how do they compare to other segments of the target population?
- Are there related consumerist behaviors that might predict receptivity to quality information?
- What triggers the decision to act and/or seek out information?
- Where do caregivers turn for information when they decide to act?
- How receptive are they to information about quality?
- What are the strategic communication implications of these characteristics and behaviors to public reporting campaigns and messages?

This report describing project findings is divided into four sections. Section I outlines the research methodology; Section II presents a selective review of the relevant research; Section III discusses key findings from qualitative research conducted with caregivers, general consumers, and formal information intermediaries; and Section IV discusses implications for communication strategies and messages.

SECTION I. METHODOLOGY

This report synthesizes and summarizes findings from research using two methodologies: a selective review of reported research and focus group research with caregivers, consumers, and key information intermediaries.

Selective Research Review

On a continuing basis for the duration of this Subtask, the research team reviewed relevant CMS-sponsored research and studies identified through the Pub Med database related to the following areas of interest:

- Characteristics of family caregivers and their role in decisions regarding nursing home and home health placements;
- Consumers' and caregivers' uses of health care quality information; and
- Factors related to the processes and timing of decisions about home health and nursing home placement

Together with CMS project officers, the Barents team identified 26 research reports and studies that the team had not reviewed previously, which were deemed to be relevant to the research questions or study design of this Subtask.

Focus Groups

While the primary focus of this Subtask is on the potential use of quality information by "early adopters," the study team and project officers determined that those who display the specific behavior of interest (i.e., using available quality information to select nursing homes or home health agencies) are likely to be too rare to be readily identified and studied directly. The project team therefore decided to conduct focus groups with representatives of the following groups of consumers and intermediaries involved with beneficiaries and their caregivers "upstream" in the planning and decision process:

- Caregivers and/or Medicare beneficiaries who have sought information or support regarding their own or their loved ones' future long-term care health needs;
- General consumers who have demonstrated advanced planning for future needs; and
- Formal information intermediaries in the care and decision-making process who assist beneficiaries and caregivers in placement decisions.

The research team selected Camarillo, California, Providence, Rhode Island, and the Boston metropolitan area in Massachusetts as research sites because of the demographic mix of their populations; their history of public reporting and/or public use of quality information; a prior history as pilot demonstration sites for Medicare quality reporting initiatives; the presence of relatively integrated health care delivery systems; and the availability of appropriate research facilities. Using screening criteria designed to identify individuals who had engaged in related planning and/or placement activities in each of the three groups identified above, professional research facilities recruited research subjects at each of the sites. Recruitment criteria and a description of respondent characteristics are included in Appendices A and C.

A two-person study team conducted a total of 12 focus groups at the three research sites from July 10 to July 19, 2002. Structured protocols for each category of respondents were designed to explore when caregivers might begin to be receptive to information that would help them plan, what it is that prompts their concern, and what other sources of support or information they turn to. One member of the study team conducted the focus group while the second observed and took notes. Each group was also audio and videotaped. At the conclusion of each day of field research, the members of the research team compared notes and impressions and reviewed findings with the project officer. Copies of the moderators' guides for the three groups are attached as Appendix B.

SECTION II. SELECTIVE RESEARCH REVIEW

The Barents team, together with CMS project officers, identified research reports and studies not reviewed previously, which were deemed to be relevant to the research questions of this Subtask. Salient findings from these studies are summarized below.

The challenge of older consumers

In describing the issues that CMS would confront in its efforts to inform Medicare beneficiaries and older consumers about health care quality and promote more informed consumer choice, Shoshanna Sofaer (Sofaer, 2000) summarized what she had learned from her own research over the years. Consistent with findings from CMS-sponsored studies that the project team reviewed earlier (Barents Group, 2001), Sofaer described a cohort of older Americans with limited awareness that health care quality might, indeed, vary; a tendency to judge quality based on the individual characteristics of their caregivers, rather than objective measures of clinical quality; and inclined to defer to the judgment of their (trusted) clinicians, rather than seek out information to make their own independent health care decisions. Older Americans, she observed, also often depended on family and friends as guardians, caregivers, sources of information, and surrogate decision makers. But the burden of the caregiving tasks often left friends and families with little time or energy to examine quality issues, much less seek out comparative information about quality. As a result, she observed, most older consumers and their caregivers responded to crises, instead of planning ahead. The demand for quality information was almost nonexistent. "Providing comparative information in this context is an uphill battle," she concluded, "since many do not recognize its relevance to their lives."

Sofaer's observations were also confirmed by staff and volunteers from state health insurance counseling programs (SHIPs) who participated in a series of focus groups Sofaer conducted for CMS in 2001 (Sofaer, 2001). SHIPs' staff and counselors confirmed that clients often sought help in times of crisis and that they expressed little interest in quality, except in terms of trust in their own personal doctor.

The tendency of older age cohorts to defer to the authority of physicians, rather than make independent judgments based on their own evaluation of the evidence, was also attested by physicians participating in a Veterans' Health Administration study of patient education materials designed to promote shared decision-making (B. H. Snyder, 2001). The physicians participating in this study observed that the World War II veterans among their patients asked the fewest questions; the Viet Nam veterans were more argumentative; and Gulf War veterans were most knowledgeable and asked the most questions. Whether the younger age cohorts will continue to question authority as they age (as Sofaer and others have suggested will happen as "baby boomers" age) or adopt the more deferential posture of the current generation of elders remains to be seen.

Family and other caregivers

Family caregivers are potentially important information intermediaries for older consumers making health care decisions – not only because, as Sofaer has suggested, they often serve as proxy decision makers as well as sources of information, but also because younger caregivers may have more in common with the questioning Viet Nam or Gulf War veterans that Snyder's informants described, and thus be more willing to actively seek out and use quality information. In support of this view, the Pew Internet & American Life Project's telephone survey of Internet users found that an estimated 73 million American adults, or 62% of all users, actively go on-line to seek out health information (Fox and Rainie, 2002). Of these, 81% are looking on behalf of someone else, and 38% are actually caring for someone else. Proportionately more of these "health seekers" are in the 50-64 age range, but younger users (who are, presumably, more internet-savvy) are more likely to find what they are looking for. However, regardless of age, those who look for health information on the Internet are not particularly critical of the quality of health information on the Internet: fully 72% of all such "health seekers" say that you can believe most or all of the health information online.

A profile of family caregivers also emerges from several recent national studies. In their review of then-current studies (including surveys conducted by Family Circle and the Kaiser Family Foundation; by the National Alliance for Caregiving and the American Association of Retired Persons; and by the National Council on Aging), the Academy for Educational Development (AED) reported that an estimated one in every four households in the U.S. was involved in caregiving, with about 25 million providing assistance to older adults (Academy for Educational Development, 2001). The most common informal caregiving relationship (38%) was that of the adult child of elderly parents. Although women were once thought to predominate among caregivers, AED found that their demographic characteristics generally mirrored those of the general population. Caregiving covered a spectrum of activities, they found, including (most often) help managing finances and supervising outside services. Sixty-four per cent of caregivers said that they talked to their older relatives about Medicare, and 44% provided some sort of information or help with Medicare. More than half were somewhat or very interested in learning more about Medicare, and two-thirds were generally unaware of basic issues regarding Medicare coverage. A substantial minority (30%) expressed concerns about the quality of medical services their loved ones received. And many searched for information on the Internet. However, most caregivers also had to balance work and family life, which may have left little time to search for information. An estimated 70% worked (57% full time and 13% part time), and more than half reported having to make changes in their work schedules to accommodate caregiving responsibilities. Forty per cent of caregivers also had children under the age of 18 living in their households.

Augmenting this statistical profile with qualitative research with caregivers, AED and Alan Newman Research found that although helping older adults covered a broad spectrum of activities, most people equated the term "caregiver" with personal, hands-on care and therefore did not think of themselves in those terms (Academy for Educational Development and Alan Newman Research, 2001). Reaching caregivers early in the caregiving continuum, when they are most in need of information and less likely to be facing a crisis, will therefore require a different terminology. Relatively few of the caregivers (broadly defined) participating in this research were familiar with Medicare channels of information (telephone, print, or website), although most responded favorably to the concept of comparative information on quality and (with a few notable exceptions) most considered Medicare to be a credible source of such information.

The burden of caregiving among those at the more intense end of the continuum is suggested by statistics gathered by the Robert Wood Johnson Foundation (RWJF) and the Foundation for Accountability (FACCT) in an on-line survey of 1,005 identified caregivers of the chronically ill (Robert Wood Johnson Foundation and FACCT – The Foundation for Accountability, 2002). Among this population, feelings of isolation were common (55%), and many (50%) reported that the burden of caregiving was sometimes or frequently "too much to handle." In this group, too, children were most often providing care for their parents (37%), followed by spouses (19%) and other relatives (11%). Most had become caregivers by default – either because they happened to live close by, or because they were the only relative with enough time to help. Most provided help with four or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs), most often with intermittent activities such as shopping, driving, housework, and cooking. A smaller proportion reported helping with more fundamental ADLs, such as dressing, walking, bathing, incontinence care, or feeding. However, the burden associated with these latter tasks was often cited as a major reason for seeking placement in a long-term care facility. A substantial majority of caregivers (60%) also reported coordinating medical care for the relative in their charge. However, many found it difficult to get needed services, both for financial reasons and because of the "hassle factor" associated with finding out what they needed to know. Most caregivers knew how to arrange for nursing home care, but few understood about the scope or nature of services subsumed under home health care. In terms of planning for the future, most reported that the necessary legal steps that would make future decisions easier (living wills, powers of attorney) had not been taken.

Barriers to change

This last observation suggests that even the chronically ill and their caregivers are resistant to planning for the future. Most of them, it seems, would fall (at best) into the category of *Precontemplators*, according to the transtheoretical model of behavior change – that is, recognizing (perhaps) that they ought to do something, but still not taking any action. This reluctance to anticipate, much less plan for, future dependency or long-term care needs, even in the face of apparent disability or functional decline, is a common theme in the literature. In their thematic analysis of caregivers' decisions to place family members with Alzheimer's Disease into a nursing home, Butcher and colleagues found that many study participants felt ill prepared for the placement decision, even though they had long known that the need for such a placement was "looming on the immediate horizon" (Butcher and others, 2001). Travis and McAuley, in their study of factors surrounding searches for nursing homes, distinguished "anticipatory" and "non-anticipatory" search behavior as well as "time-pressured" versus "non-time-pressured" searches (Travis and McAuley, 1998). Time-pressured searches (such as those precipitated by a medical crisis and acute-care hospitalization) predominated, they found, even in cases when the eventual need for long-term care was anticipated in advance. Needs assessment research conducted by the Barents Group for CMS's nursing home consumer choice campaign also found that most caregivers do not seek out information about nursing home information until a health crisis occurs, because of guilt and stigma associated with placing their loved ones in nursing homes (Barents Group of KPMG Consulting, Inc., 2002). Other smaller qualitative studies of family caregivers' experiences reported in the literature showed similar findings (Ryan and Scullion, 2000; Noonan, Tennstedt, and Rebelsky, 1999; and Rodgers, 1997).

What makes behavior change when it comes to planning ahead for long-term care especially difficult, of course, is the emotional resistance most people have to thinking of themselves (or their loved ones) in a dependent state. A cognitive mapping exercise undertaken by Barents Group researchers in focus groups with Medicare beneficiaries about long-term care revealed that most liked to think of themselves as "aging vibrantly" and "dying quickly," thereby actively avoiding the issue of ever needing long-term care (Barents Group of KPMG Consulting, 2001). Respondents acknowledged that they were in denial: "None of us wants to think about the inevitable. We should, but we won't." However, they firmly believed that it was important to maintain a positive attitude instead of "thinking old." Planning for long-term care, they thought, was a guarantee that one would need it.

Carrese and others found remarkably similar attitudes, even among chronically-ill housebound patients over the age of 75 living in the community (Carrese, Mullaney, Faden, and Finucane, 2002). Of 20 such patients interviewed, 19 were particularly reluctant to think about, discuss, or plan for a serious future illness, in spite of their existing disabilities. Although many had made "final arrangements" for their death, they preferred to focus on living in the present, living one day at a time, and leaving the rest "to God." As one woman observed, "I mean, why worry about it? What's going to happen is going to happen and I believe in crossing that bridge when you get to it, you know."

This reluctance to think about future serious illness or health care needs also means that both older people and their family caregivers are generally unfamiliar with the range of available services for dependent elders, except for nursing home care. In testing a booklet about long-term care with Medicare beneficiaries and their caregivers, researchers from Equals Three Communication found that even those currently enrolled (or planning to enroll) in some services tended to equate "long-term care" with nursing homes or hospice, rather than a range of services along a continuum (Equals Three Communications, 2001). As one respondent commented, "Unfortunately, I think of long-term care usually before you pass away. That's the end." Most respondents were unfamiliar with concepts such as respite care or with the range of home health services.

Barents Group researchers testing OASIS measures of home health quality with family caregivers also found that consumers understood very little about what home health entailed, making it difficult to elicit their responses to the proposed quality measures (Barents Group of KPMG Consulting, 2002). Even when consumers had received home health services in the past, they often confused homemaker services, companion care, and hospice, and seemed unaware of the range of skilled services available, beyond those that they, themselves, had received. Physicians and discharge planners confirmed that most of their patients and family members understood very little about home health services (Barents Group of KPMG Consulting, 2002).

Trajectories of decline and triggers to action

Joanne Lynn has attributed failure to plan appropriately for end-of-life care to fundamental misconceptions about common trajectories of decline (Lynn, 2001). Conventions surrounding hospice care, for example, assume that death will be preceded by an obvious, precipitous decline. While this may be true with some terminal illnesses, Lynn argues that the more common trajectory in old age is a long and relatively gradual decline in functional status, punctuated by crises, or episodes of acute illness. Lynn's main point, because her interest is in care of the dying, is that the timing of death is not easily predicted. Any given crisis, if it is severe enough (or if the patient's underlying health has declined enough), can take the patient away – apparently quite suddenly. Yet patients can, and often do, recover from such episodes, even if they rarely return entirely to their previous level of function.

In these instances, family caregivers may fail to plan ahead because they become accustomed to the intermittent crises and assume that their loved one will (once again) bounce back. This may explain why even those who presumably have advance warning fail to take action until their loved ones are either in crisis or in fairly advanced states of decline. As suggested above, the literature on nursing home placements confirms that most take place in time-pressured circumstances following a crisis, often after long periods of home care by informal caregivers (Travis and McAuley, 1998; Ryan and Scullion, 2000). Even in the face of certain decline, as in the case of patients with Alzheimer's Disease, family members resist planning for placement until they have reached the "breaking point," when they are no longer able to care for the patient at home (Butcher and others, 2001). Physicians (Barents Group of KMPG Consulting, 2002) and caregivers (RWJF and FACCT, 2002) confirm that family caregivers actively seek help (in the absence of such precipitating events) only at fairly advanced stages of decline – when patients need continuous help with such basic functions as feeding or incontinence care.

Another way to look at this trajectory, however, is to see the acute episodes as "sentinel events" that often signal (or precipitate) new levels of functional decline. Because such events often result in hospitalization and (therefore) contact with teams of medical professionals, Covinsky and colleagues have seen them as opportunities for intervening in the lives of elderly patients (both clinically and behaviorally) at earlier stages in the trajectory to maintain as much independence as possible and slow the process of decline (Covinsky, Palmer, Counsell, and others, 2000).

Characteristics of advance planners

The studies reviewed for this report attest to the factors that impede the use of quality information to plan ahead for long-term care. Overall, however, they provide little insight into the behaviors and motivations of those potential "early adopters" who are the focus of this Subtask – namely, those who *do* plan ahead. Tellingly, these types of individuals showed up too rarely in most studies to attract much attention – with the following notable exceptions:

- Of the 25 caregivers responsible for placing nursing home residents interviewed by Travis and McAuley (1998), only 6 had engaged in "non-time-pressured/anticipatory" searches.

These appear to have been relatively advanced cases of dementia, Alzheimer's disease, and extreme old age (100 years plus).

- An unspecified number of the 30 family caregivers of patients with Alzheimer's Disease interviewed by Butcher and colleagues (2001) had anticipated the need for placement and had made an effort to become acquainted with the Special Care Unit in advance. The investigators suggest that the involvement of health care professionals in the decision-making process appeared to ease the burden of guilt and betrayal among family caregivers, making it easier for them to accept the inevitable and plan ahead. They also found that some study participants were more likely to plan ahead for their own future needs as a result of their experiences with their loved ones.

- The Equals Three Communications (2001) research team found that the few "planners" participating in focus groups testing Medicare's "Choosing Long-Term Care" booklet were somewhat more likely than others in the group to understand that long-term care represented a continuum of care needs and a range of services (although they, like the others, thought mainly in terms of nursing home care). However, these "planners" thought first in terms of insurance needs, and thought that planning for care or services was difficult, because "in the end, . . . your financial situation will dictate what your options are."

- The Barents Group research team conducting Long-Term Care Focus Groups in October 2001 found a few individuals who appeared actually to be planning for long-term care, but these individuals did not clearly indicate what motivated them to do so. Some of the single women participating in the groups "appeared more realistic" in thinking about aging and spoke of moving to be closer to their children when they got "old." Some caregivers who had dealt with their own parents' long-term care needs were also more receptive to information about their own options, because they could conceptualize the urgency more readily. As one respondent commented, "After what I went through with my mother, I realized that even small things can make a difference."

Understanding and using quality measures

In a recent journal article, Davies, Washington, and Bindman express concerns about the implications of health care report cards on vulnerable patient subgroups and the organizations that care for them (Davies, Washington, and Bindman, 2002). In particular, they questioned (1) the *relevance* of many quality measures to many consumers, arguing that they focus on qualities that are easily measured rather than the day-to-day issues of most concern to consumers; (2) the *meaningfulness* of rankings or categorizations, in terms of accurately reflecting differences in performance; and (3) the potential *use and misuse* of the data, including the possibility of creating perverse incentives and dysfunctional effects. Indeed, the research with consumers and family caregivers reported here, across a variety of studies, confirm that most consumers understand quality in personal identifiable terms, rather than in terms of clinical outcomes often reported in quality measures (making their *relevance* questionable).

For example, most caregivers evaluate nursing homes on the basis of cleanliness, caring, and staffing, taking clinical performance more or less for granted (Barents Group of KPMG

Consulting, 2002; Butcher and others, 2001). In addition, both consumers and physicians participating in focus groups testing OASIS measures (Barents Group of KPMG Consulting, 2002) found it difficult to relate to the measures as indicators of how well the home health agency performed in providing care, suggesting that they did not readily perceive them as *meaningful* in the sense that Davies and colleagues describe. Both physicians and discharge planners participating in the OASIS research also expressed concern about the potential for publicly reported measures to create disincentives for home health agencies to serve difficult (i.e., sicker) populations. And although all participants (caregivers and intermediaries alike) displayed interest in the measures, all indicated that they would rely on their own personal experience or the advice of others in making judgments about quality.

Hibbard and Peters' observations about how consumers process information for decision making shed a somewhat different light on consumers' and intermediaries' observations regarding OASIS measures (Hibbard and Peters, 2002). They agree that consumers need usable information, and an adequate understanding of their choices and the implications of those choices in order to feel "empowered" by quality information. However, an abundance of information does not necessarily inform choice. Consumers use two modes for processing information in decision-making: an analytic mode and an experiential mode. Proponents of quality reporting may assume that it is the analytic mode that informs choice, but in fact it is the experiential mode that provides both meaning and motivation. Most people, they add, have trouble understanding the meaning of choices with which they have no experience with these types of care. Their work also suggests that some consumers at middle ranges of comprehension who are given a narrative as well as a graphic display of comparative quality data understand it better. Although Hibbard and Peters suggest using narratives to highlight the meaning of reported quality information, the Barents' Group's OASIS research suggests that consumers and intermediaries alike may supply their own meaning by drawing on their own personal experiences in relating to the measures, or by seeking out the narratives embedded in others' advice.

McCormick et al's recently-published study showing that low-scoring health plans are likely to stop disclosing their quality data in voluntary reporting arrangements also appears to underscore Davies and colleagues' concerns about the possible deleterious effects of public reporting (McCormick, Himmelstein, Woolhandler, Wolfe, and Bor, 2002). The authors conclude that such selective non-disclosure undermines informed consumer decision-making as well as public accountability. In an editorial in the same issue, Donald Berwick acknowledges the mixed feelings about public report cards – in particular, the fear that public scrutiny will inhibit a willingness to take the risks necessary for change and improvement (Berwick, 2002). He concludes, however, that public reporting, on the whole, creates the tension necessary to overcome resistance to change.

Observations such as these remind the reader that the individual behavior examined through the research in this Subtask is ultimately supported or undermined by the larger social environment.

SECTION III. QUALITATIVE RESEARCH FINDINGS

This section of the report describes key findings about characteristics and behaviors of advance planners and likely "early adopters" of comparative quality information, triggers that prompt consumers to take action relating to dependent care needs, and perceived information needs and concerns related to quality of care.

Key Findings

Characteristics and behaviors of advance planners and likely "early adopters" of quality information

- **Those most actively engaged in advance planning for needs relating to aging are men and women upon whom the responsibility for caregiving has fallen in the past.**

  The Medicare beneficiaries and caregivers who appeared to be most clear-sighted in their approach to future care needs were the ones who had shouldered the burden of caregiving in the past. Many had taken care of a parent or a parent-in-law. They knew from experience what to expect, and they understood how feelings of anger, guilt, betrayal, and sadness made it difficult to make necessary decisions in a timely and effective manner. Their experience helped them overcome the denial and resistance so much apparent among other family caregivers. These characteristics of experienced caregivers held true across all sites, and across all incomes, educational, and ethnic groups represented in the focus groups.

  Although women had more often assumed a caregiving role in the past, male respondents also fell into this category. Many of these experienced caregivers were either only or eldest children. Others had long assumed the primary caregiving and/or decision-making role in the family. They were simply the ones that family members automatically turned to, even when spouses or other competent adults were present. They also perceived themselves as the ones who could better navigate the system and advocate for their family member. For example, one Hispanic woman in Camarillo (the eldest daughter in her family, but not the eldest child) had long been the one in her family to translate for her non-English-speaking parents and to serve as their go-between with the official Anglo world. When asked how long she had been taking care of her mother, she responded, "Oh, I've been taking care of my parents since I was five years old!"

  Experience caring for others also made these individuals more likely to plan for their own future. They did not want their family members to suffer the burnout and pangs of guilt that they had experienced, when the time came that they were no longer able to care for themselves. For example, one single woman in her late sixties, who, as the only child, had taken care of her mother in her declining years, had purchased long-term care insurance and prepared a living will for herself, although she was still very active and in good health. As she explained it, "I know what I had to go through for my mother, and I don't want my partner to have to worry about that." Another woman observed, "I would plan ahead, because it saves you lots of aggravation when you are mourning the [decline and] loss of your loved one. I know this from experience."

- **Advance planners in this category also have first-hand experience trying to gather information on long-term care alternatives. They understand the issues at stake and the value of good information.**

  Participants who had taken care of aging relatives told of how hard and time-consuming it had been to track down information about available resources and care alternatives for their relatives – everything from needed durable medical equipment to respite care. One man who had cared for his mother through a long debilitating illness said that getting information and tracking down resources had become his "full-time job." Others described the experience as "literally exhausting." In the process, however, these individuals had become very savvy at hunting down the information they needed and were far more knowledgeable than other consumers about available resources and sources of information. Several knew, for example, about the quality data that Medicare requires of nursing homes. All expressed a strong and genuine interest in publicly reported facility-specific quality information from Medicare.

- **Advance planning for needs related to long-term care and/or aging does not reflect a consumerist orientation, in general.**

  One of the working hypotheses that guided the planning of the research for this Subtask was that individuals with a consumerist orientation – i.e., those who tend to search out comparative information before making major purchasing decisions – would be the likely advance planners and "early adopters" of quality information relating to home health and nursing home services, and therefore a likely target audience for quality information. Although the study team did not target consumerists, specifically, in this research, the team did probe to determine whether identified advance planners for future long-term care needs exhibited consumerist behavior in other aspects of their lives.

  Interestingly, the advance planners described above did not report a markedly consumerist approach in other respects. They were motivated by *experience*, not by consumerism. As one respondent stated, "choosing a nursing home is *not* like choosing to buy a car."

- **Male heads-of-household accustomed to assuming the fiduciary responsibilities of the family may represent a distinct category of individuals motivated to plan ahead for needs relating to aging, regardless of prior caregiving experience. However, they appear less emotionally engaged in the process than those with prior caregiving experience.**

  A small number of focus group participants who lacked prior caregiving experience, notably male heads-of-household from relatively affluent backgrounds, appeared to be motivated to plan ahead for a variety of needs by a more traditional paternalistic sense of responsibility for the family's welfare. They also appeared to be active consumers of comparative information, generally, and to regard themselves as the person responsible for making informed decisions for the family. Planning ahead *before* there is a crisis also appeared to be a strong part of their self-image and their reported motivation, and they likened decisions around health care needs to decisions around life insurance or estate planning.

However, in contrast to the advance planners who had prior caregiving experience, these individuals appeared to keep their emotional distance from the planning process, even when they had aging relatives for whom they were responsible. They took almost an intellectual approach to contingency planning and did not appear to connect the exercise to any real anticipated needs that their loved ones might have.

Several discharge planners participating in the intermediaries' focus groups reported that these are the types of individuals most likely to come to meetings armed with checklists and information downloaded from the Internet. "They're the hardest ones to deal with," reported one discharge planner. "They don't *really* want to talk about what's going on." Notwithstanding their emotional distance and even denial, these individuals appeared to be receptive to factual information and to offers of help that would allow them to engage in planning and information gathering in a detached and systematic way.

Because only a small number of respondents displayed these characteristics, however, these observations are merely suggestive. Further research is needed to probe whether such individuals may be true "early adopters" of quality information.

- **When family members come together to care for aging relatives, men may assume the role of planners and information gatherers, while women may assume the role of caregivers.**

Key informants interviewed prior to the field research suggested that adult daughters of aging parents were a likely target audience for comparative quality information, because they are the ones who actually take care of their parents. However, the research team found in the focus groups that men as well as women are likely to have been caregivers in the past, as suggested above. Moreover, information intermediaries reported that it was often men who came to them actively seeking comparative information about nursing homes. Several respondents suggested that there is often a sort of division of labor in families, where women deal with the physical care and emotional issues, and men gather information (which allows them to maintain their emotional distance). As one male respondent noted, "You have to do the research." However, the limitations of this research did not allow the study team to probe gender roles in any depth.

- **Advance planning for funerals is common, but it is *not* associated with advance planning for health care or other needs related to aging.**

Advance planning for funeral and burial arrangements was common among men and women of all income and education levels at all sites. Many respondents noted that they picked up information when attending a funeral of a family friend and saved the brochures for later use. Pre-payment for funerals was also common, especially among lower income focus group participants in Providence and Boston, who did not want their children to have to worry about such things during a difficult time. However, this behavior does not necessarily reflect a realistic approach to dependency needs related to aging or a willingness to plan ahead for such contingencies. Several respondents commented that choosing a nursing home is much harder than planning for a funeral. Death is recognized as inevitable, but the declining health and dependency that precede death are not topics most people care to think about. As one male respondent explained, "Planning for a funeral is different than planning for my mother to go into a nursing home. She is still *alive* in a nursing home."

- **Only children, especially those who are single, also recognize the need to plan ahead, but they often do not know what to expect or where to turn for help.**

  Only children often recognized that they were the ones who would have to take care of their parents if something were to happen, noting with concern that "there is no one else that could help." They also acknowledged that it was important to plan ahead for contingencies. Unless they had prior caregiving experience, however, they found it difficult to think about what might happen and seemed reluctant to take action until problems arose. When pressed, however, most thought that having information available early on would be useful.

Triggers to action

- **Witnessing problems relating to aging and functional decline in other people's relatives can prompt concern about one's own.**

  Consistent with findings from other research, respondents across all focus groups at all sites commented on the difficulty people have coming to terms with their own functional decline or their parent's or spouse's increasing dependency. However, many focus group respondents exhibited *no* difficulty recognizing this trajectory (and acknowledging its implications) when it occurred in in-laws or other people's relatives. Several remarked, when describing their family situation, that they would most likely be the ones who would have to "step in," because their spouses were unable or unwilling to face the truth about their parents. A number of the experienced caregivers had, indeed, gained their experience and insight by caring for failing in-laws rather than their own parents. And this experience, they said, made them better able to recognize their own parents' or spouses' needs when they began to fail. As one male respondent observed, "I have to be careful not to cross the line of her [mother's] independence and dignity, but also let her know that she may need outside help."

  Hospital discharge planners also reported that adult children sometimes approached them for information about long-term care alternatives after visiting the ailing relatives of long-time friends. "When you see it happen to someone else, you realize it can happen to you," explained one.

- **Experienced caregivers and intermediaries recognize triggers of concern further "upstream" in the trajectory of functional decline.**

  When asked what first prompted them to think about their loved ones' needs and start planning for the future, respondents who were experienced caregivers, especially, were likely to mention relatively subtle signs and signals that occurred long before there were serious signs of decline. Several said that they began to make plans when their parents' or in-laws moved "back home," "close by," or in with their children. Even though none reported that these relatives were in failing health at the time, they recognized that the parents themselves were sending signals through their actions. It was because of their past experience and the recognition that they would (again) be the ones shouldering the caregiving responsibility that they were able to pick up on these signals.

Hospital discharge planners as well as experienced caregivers also mentioned loss of a car, driving license, or the inability to drive as a trigger of concern, because it often triggered reliance on others for basic needs, such as getting to the store for food and medicines or getting to medical appointments. Several respondents noted that older people's ability to function independently began noticeably to decline when they could no longer drive. This was mentioned especially in California, where there was greater reliance on personal automobiles for transportation. In some cases, it was the aging parents, themselves, who voluntarily gave up driving, especially after an accident. Here again, the parents were sending signals of their own.

- **Most caregivers who lack prior experience delay taking action until there are more obvious signs of decline, further "downstream" in the process.**

The triggers of concern that caregivers identified most often were those associated with more serious states of decline that virtually demanded intervention: hospitalization; falls or serious mobility problems; leaving things burning on the stove; not eating; wandering; not answering the telephone. These individuals also acknowledged their reluctance to take action until it was absolutely clear that their parents or loved ones could no longer function on their own. When pressed, however, most respondents acknowledged "earlier signs" of decline, such as deteriorating personal hygiene or housekeeping, that had prompted concern but not action.

Perceived informational needs and concerns about quality

- **Most caregivers express the need, first, for information about available services and their covered benefits. Concerns about quality arise once they have a clearer understanding of available alternatives.**

Unless they have prior experience, most caregivers are at a loss as to where to turn for help when their elderly family members can no longer function independently. Apart from nursing homes, they usually know very little about the kinds of services that are available, how much they cost, and how they can be paid for. Experienced caregivers confirm that finding this information requires time, effort, resourcefulness, and persistence. As one respondent who had cared for a mother with dementia put it, "it becomes a full-time job."

Although it was not the first thing they mentioned, all caregivers agreed that quality was a major concern when it came to making plans for their family members. As one woman expressed it, "you want the best – or at least the best that you can afford." Hospital discharge planners also confirmed that family members often raise questions about the quality of care in nursing homes and home health services, once they have determined their alternatives.

- **Most caregivers are acutely aware of issues regarding the quality of care in nursing homes.**

  Many family caregivers expressed concerns about the quality of care their loved one would receive in a nursing homes, reinforcing their natural resistance to even considering nursing home placement for their parents or spouses. "I would never do that to my mother!" one respondent insisted, expressing a common sentiment shared by many others. For the most part, negative images of nursing homes appeared to be deeply embedded in the culture, rather than based on experience. In some cases, too, stories about poor quality care in particular homes had been sensationalized in the news media and widely circulated by word of mouth. Several respondents mentioned recent sensational stories connected with local nursing homes.

  Yet these concerns have the effect of raising caregivers' awareness and motivating them to become acutely aware of the importance of quality in nursing homes, creating an opportunity for communicating about variations in quality. After hearing about the availability of quality information, for example, several respondents commented that they would be very interested in learning more about good nursing homes and acknowledged that their inherent feelings of guilt about placing their parents would be minimized if they knew that good alternatives existed.

- **Caregivers' concerns about home health services relate more to discomfort with "strangers in the house" than to concerns about quality.**

  Although most caregivers relied on hospital social workers to arrange for post-acute home health services following a hospital discharge, many also had experience arranging, or trying to arrange, for other services to help their family members at home – some of which were covered by Medicare or other forms of public assistance and some of which were private pay. In contrast to the concerns they expressed about nursing home care, however, caregivers raised few questions about the quality of home care services. Instead, what family members mentioned most often was their discomfort with having strangers into their or their parents' house. (This was particularly the case when care extended beyond immediate post-discharge skilled nursing needs.). In some cases, caregivers acknowledged that their parents actually seemed to "enjoy the company," but they (the adult children) still did not like the idea. Several adult children spoke disparagingly of home health workers who "sat around the kitchen and drank coffee" with their parent instead of doing their work. Others complained that home care workers "took over the house." As one woman explained, "This was the house that I grew up in, and I felt as if they were taking it over." Surprisingly, this aversion to care in the home was sometimes stronger than the aversion to assisted living or institutional long-term care.

- **Caregivers as well as intermediaries express interest in comparative facility-specific information about quality. However, they are most likely to use it in conjunction with other, more subjective, sources of information.**

Although caregivers' receptivity to comparative quality information clearly varies, with advance planners exhibiting the most active interest, *all* caregivers expressed interest in such information when it was explained to them. However, most stressed that they made judgments about quality (and would continue to do so) based on other information – including cost, the recommendations of family and friends, health professionals, and their own personal observations. Hospital social workers and discharge planners also expressed interest in the information, but they, too, made judgments based on prior experience with placements, personal relationships with particular agencies or their staff, and other subjective factors. They also urged family members to visit various nursing homes and make their own judgments, based on their personal observations.

- **Hospital social workers and discharge planners are important sources of information to family caregivers. However, the caregivers who are most actively engaged in advanced planning activities for their family members seek information from many, varied, and disparate sources.**

Family caregivers at all sites reported that they received information about nursing homes and home health care services from hospital social workers and discharge planners when their parents or spouses were in the hospital, or shortly after they were discharged. Discharge planners also reported that family caregivers often came to them asking for this information. However, hospital-based intermediaries and informational resources became involved, in most cases, only fairly late in the game, after a family member had experienced a sentinel event in the trajectory of decline. Moreover, the information that these information intermediaries provided addressed only some of the caregivers' concerns.

Experienced caregivers therefore stressed the importance of gathering information in many different ways and from many different sources. Most reported having tapped family and friends for information, calling around to many different community agencies and resources, searching in libraries, phone books, and on the Internet. No single source of information emerged from these experiences as most important or primary.

SECTION IV. IMPLICATIONS FOR COMMUNICATION STRATEGIES

This section of the report describes implications for communication strategies that CMS might consider in its national implementation of nursing home quality information and its upcoming quality initiative around home health care.[5]

- **Target "early adopters"/advance planners as the primary caregiver audience.** This research suggests that there may be two distinct groups of caregivers who have the potential to plan in advance for the dependency needs of aging family members:

  1) *Experienced caregivers* – *Medicare beneficiaries or current family caregivers who also have prior caregiving experience,* and

  2) *Heads-of-household* – *Members of the household (usually heads-of-household, often male) who assume fiduciary or estate-planning responsibilities for the family.*

  Although more research is needed to determine the potential of heads-of-household to be "early adopters" of quality information, both of these groups may be considered primary target audiences for facility-specific quality information from Medicare.

- **Frame messages to tap into their personal characteristics and motivation.** The characteristics and motivations of each of the primary audiences identified above appear to be quite distinct.

  Experienced caregivers understand, from past experience, how difficult it is emotionally to deal with a loved one's functional decline and loss of independence. It is because *they know what to expect* that they recognize the importance of planning ahead and being prepared. They may therefore be responsive to messages that acknowledge and tap into this emotional "realism." For example, messages might be framed as follows: *I know how hard it was to admit that my mother couldn't take care of herself any more. I had no idea where to turn for help or information. I wish I'd known then what I know now. Medicare is one place to turn for information.*

  Male *heads-of-household* who lack past experience with caregiving, however, may *not* be emotionally prepared to deal with a loved one's functional decline. In fact, some respondents suggest that for them, planning is a way of maintaining distance from an emotionally difficult situation. They may therefore *resist* messages based on an emotional appeal, but respond to those that appeal to their rational side and their sense of paternalism while allowing them to remain in emotional denial. For example: *My family relies on me to plan for the future, and they turn to me to know what to do when there's a crisis. Mom's 85 and she's doing fine.*

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[5] The Quality Improvement Organizations (QI0s) working under contract to CMS to support their quality improvement initiatives may also consider these strategies in designing communication campaigns targeting consumers and information intermediaries.

She's amazing, keeps on going like the Energizer bunny. But I know Medicare is one place I can count on for reliable information, if we ever do need help.

♦ **Target "contemplators"[6]/potential planners as a secondary (alternative) caregiver audience (for example, only children or sole caregivers).**

Only children or others who are the sole caregivers of elderly relatives often recognize that they are likely to be the ones who will be responsible for taking care of the aging relatives and making decisions about home care or nursing home placement when they are no longer able to care for themselves. However, they may lack the emotional readiness or the motivation to take action that experienced caregivers or male heads-of-household have. As *"contemplators"* who can be encouraged to take the next steps toward taking action through targeted campaigns, these individuals should be considered a secondary target audience among caregivers.

♦ **Frame messages to move "contemplators" to action by honing in on triggers, while acknowledging emotional resistance.**

The challenge in motivating c*ontemplators* to take action lies in getting them to recognize potential needs before they reach crisis stage, and to recognize that planning ahead for such needs does not constitute a betrayal. They may be responsive to messages that focus on triggers such as seeing bad things happen to other people, or to messages that help them acknowledge "upstream" signs and signals that the relatives themselves might be sending (such as moving close by or giving up driving). These messages might be framed along the following lines:

◊ *I'm the only family my mom/dad/aunt has. He/she is doing fine, so far (knock wood). But I saw how hard it was for my friend when her mother got sick. She found out that Medicare has information that can help. I think I'll give them a call.*

◊ *Mom and dad have decided to move back to town so they can be closer to me. I'm all they have. They're doing fine right now, but still, I worry. I found out that Medicare has information that can help me plan ahead.*

◊ *Dad just gave me the keys to his car. He doesn't want to drive any more, ever since the cop pulled him over for driving 25 mph on the Interstate. He's doing OK otherwise, but I can't help but worry. I need to start thinking ahead. I hear that Medicare has some information that might be useful.*

♦ **Target hospital social workers, physicians and discharge planners as a primary intermediary audience.**

Although experienced caregivers report gathering information from many different and varied sources, hospital social workers, physicians and discharge planners are consistently

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[6] The term "contemplator" refers to the stage model of behavior change, as discussed in the Introduction of this report.

identified as playing an important role. They should therefore be considered the primary target audience among information intermediaries.

- **Frame messages to encourage intermediaries to engage in anticipatory guidance with family caregivers, focusing on "upstream" issues.**

  Experienced hospital social workers and discharge planners are very familiar with patterns of decline among the elderly, and they can readily identify early warning signs. They are therefore in an excellent position to provide anticipatory guidance to family members, and they sometimes report doing so when family members come to them for advice.

  However, this and related research with hospital discharge planners suggests that they tend to focus more often on the immediate need to arrange post-hospital care rather than on longer-term care considerations. Moreover, they often become involved relatively late in the trajectory of decline.

  The challenges here, then, are to encourage information intermediaries to see their job in larger terms, so they can help families recognize and plan for care needs in advance and provide them with easy to use tools so as to minimize the additional burden that this role would entail. They might be encouraged to engage family caregivers during a less serious hospitalization, rather than in a crisis situation. Messages in professional journals, newsletters, electronic listservs, or other media might appeal to their professionalism to this end, along the following lines: *'Mom will be fine as soon as we get her home.' How often have you heard that? Families don't know what to expect, but you do. You can help them plan ahead. And Medicare has information that can help.*

- **Disseminate information through a variety of channels in the local community, to reach family caregivers and raise their awareness before they are in crisis.**

  Reaching caregivers before their loved ones are in crisis poses challenges, since there appears to be no identifiably dominant "upstream" sources of information. However, respondents reported spending a lot of time sitting and waiting while they accompanied their family members to various appointments and suggested that they would be likely to pick up and notice information relating to caring and planning for aging relatives at those times. Doctors' offices, emergency room waiting rooms, and pharmacies were mentioned most often, along with libraries, post offices and other community locations. SHIP programs and counselors may be another channel for disseminating information about nursing homes and home health before the need actually arises.[7]

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[7] Beneficiaries and caregivers participating in this study did not readily identify SHIP counselors as information intermediaries. However, research conducted with SHIP counselors elsewhere (Barents Group of KPMG Consulting/Ketchum Public Relations, under contract to CMS, "NMEP Assessment of Case Study Sites," Final Annual Report, August 23, 2002) suggests that many, if not most, of their clients fall into the "advance planner" category.

- **Acknowledge and build on concerns about the care provided in nursing homes to promote interest in quality.**

  Most caregivers acknowledge that quality is important, but it is not the first thing that comes to mind in planning for health care needs of the elderly ─ perhaps because most lay people do not know how to think about or judge health care quality. However, most people *have* heard stories about poor quality of care in nursing homes, through the media and this is part of what feeds their resistance to even thinking about placing loved ones. Ironically, this negative image of nursing homes may provide a "hook" for prompting discussion and raising awareness about variations in quality performance and about measures of quality. Many respondents indicated that they would be relieved to learn that some nursing homes were good by seeing "good" data, suggesting that it would make them feel less guilty about placement decisions and more likely to broach the topic with their loved one. Messages might acknowledge the legitimacy of these concerns and the feelings of guilt and betrayal that accompany them, but offer a positive solution:

  - *I had heard terrible things about nursing homes, and I always said that I would never send my mother to one of those places. So, when it finally got to the point where I couldn't take care of her any more, I just didn't know what to do. I wish I'd known then what I know now: there really are some very good places out there that do a wonderful job – much better than I could do on my own. And Medicare has information that can help you find them.*
  - *For the longest time, I didn't even want to* <u>*think*</u> *about the possibility of putting my dad in a nursing home, much less talk to anyone about it. But talking about it doesn't make it happen, and I finally realized that the best thing I could do for my dad was to be informed.*

- **Frame messages around quality information within the context of larger issues related to planning.**

  Experienced caregivers describe having overwhelming needs for information about available long-term services to help care for dependent elders, their costs and coverage, and their quality. Within this broad spectrum of needs, information about the quality of Medicare-covered services in nursing homes and home health agencies covers only a very narrow band. Facility-specific quality information provided by Medicare cannot by itself help consumers make meaningful decisions. It should therefore be promoted as *part of* a larger set of information that can help consumers plan ahead, such as information about community resources for the elderly, private pay services, and alternatives for low-income families.

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APPENDIX A- INTERVIEW GUIDES

Moderator's Guide
Caregiver/General Consumer Audience

Dates: July 10 to July 19
Locations: Santa Barbara/Camarillo, CA; Providence, RI, and Boston, MA
Project: Describing Target Audiences for Facility Specific Quality Information Provided by Medicare

Note: The aim here is to trace the trajectory of functional decline in elderly and factors that trigger concern among adult children/caregivers, including people on Medicare that is a spouse/significant other to another person on Medicare, prior to acute episodes or crisis situations that require them to take immediate action. The point here is to find out when they begin to be concerned about their parent(s), spouse/significant other (and when, therefore, they might begin to be receptive to information that would help them plan), build on what we already know about what it is that prompts their concern (so that messages can be framed accordingly), and what other caregivers/people who are on Medicare who are caregivers to their spouse or significant other/intermediaries/sources of support/information they turn to at those times (so that these audiences can be identified and targeted).

A. Introduction and Warm-up

Thank you for coming. We appreciate your help.

My name is ___, and I work for an independent research and consulting firm. We've been hired by the agency that runs Medicare to help them understand how to get useful information to people, like you, who may be caring for an aging parent(s) or a spouse/significant other who is on Medicare. We want to talk to you today about some of the issues you may have faced or may be facing, where you have turned (or would turn) for help, who and what would be helpful to you. We want to build on your experiences and what you believe as caregivers to a spouse/ significant other of a person on Medicare that would help others. For the purpose of today's discussion, the term caregiver, throughout the interviews, will be defined as, "anyone, including the child/children of an aging parent(s)or a person on Medicare that is the spouse or significant other of a person on Medicare who is responsible for that persons health care needs and health care decisions."

Please be open and frank. We're not looking for "right" answers. We're recording these conversations, for research purposes, to make sure we capture everything that's said, but we will not use anyone's name or share this information beyond our research group. Also, some of our colleagues are observing behind the glass mirror.

We expect to be talking for about 2 hours. But if you need to get up to use the facilities, or whatever, please feel free to do so. Bathrooms are located ____________.

Any questions before we get started?

To start, I'd like you each to introduce yourselves (first name only), and tell us a little bit about your families.

- *Probe to establish general living situations and circumstances:*
    - *Do elderly parent(s) live close by or far away?*
    - *Do they live alone or with others?*
    - *What is the respondent's general care giving role?*
    - *How much support do respondents have in their caregiving role (e.g., from siblings, abler parents, etc.)*
    - *For caregivers that are people on Medicare a (spouse or significant other), probe to establish what they are responsible for doing in their caregiver role, i.e. what kinds of health care decisions.*

B. Current situation, status, caregiver perceptions

1. Tell me a little bit about how your (parent(s), spouse/significant other) are getting on at the moment:

- Are they able to function more or less on their own?
- If they need help, what sort of help do they need?

2. Has this changed recently? If so, how?

3. Has anything, in particular, caused you worry or concern?

- What has that been?
- Did something happen to trigger that concern? If so, what?

4. Have you acted on this worry or concern in any way? If so, how?

[*Note: If there is only one male and three females, encourage the male to speak-out if necessary.]*

C. Prior experience with help/helping professionals

For the group that has engaged in some sort of pre-planning, ask these respondents to tell us about their pre-planning and whether that has made them more inclined to look around for information for their parent(s) or spouse/significant other.

1. Have you ever had to get help for your parent(s), spouse/significant other from a person or agency outside the family?

- If so, what sort of help did you get?
- What sort of services did it entail?
- What prompted this need for help?
- Who helped arrange these services? Where did you turn for help?
- How did you know where to go for information?

- Who or what was most helpful to you then?
- Is there any sort of information or help that you wished you had, but didn't?

2. Apart from these sorts of specific care needs that we just discussed, have you ever turned to a group, agency, or individual for information, help or support?
   - For example: Some workplaces sponsor programs about caring for aging parents. Have you ever gone to one of these? *(Probe others: e.g., caregiver programs or informational materials at a hospital, doctors' offices, church, community/faith-based organizations, Internet, local senior centers, county government services.)*

   - If yes –
     - What prompted you to go there?
     - How did you find out about where to go?
     - What was it about (the program, information) that attracted your attention?
     - Do you think you were more receptive to this help, information, and support at that particular time than you might have been earlier? If so, why? What made the difference?
     - Is there any sort of information, help, or support you wished you had, but didn't?

D. Thinking about the future

1. When you think about the future, how do you expect your parent/spouse/significant other's needs will change? How will this affect you, as the caregiver?
   \- *Probe: to what extent have they anticipated increasing caregiver burden or the need for long-term care? To what extent do they expect to continue in the caregiving role?*

2. When you think about the future, what concerns you most about your parent(s), spouse/significant other? Why does this concern you?

3. Have you acted on these concerns – e.g., made any plans or arrangements, or started to gather any information that would help you make such plans?

   - If yes –
     - What have you done?
     - Where (or to whom) have you turned for help?
     - Who or what has been most helpful? Why?

   - If no –
     - What, if anything, do you think might prompt you to act?
     - Where would you likely turn for information or help?

4. When you think about the kind of help your parent(s), spouse/significant other might need in the future, what sort of information would be most helpful to you?
     - *Probe: information about local services that are available? Their costs? Their quality? For example, personal care aids, daycare etc.*

5. *If respondents do not bring this up on their own in preceding discussions, ask the following --* Whether or not you have looked for specific information to help you with your parent/spouse/significant other, have you ever looked for information about home health, nursing homes, or other long-term care services?

E. Medicare information

1. Have you looked to Medicare for information?
    - If so, what sort of information (briefly) were you looking for?
    - How did you contact Medicare? (phone, through print materials, website)
    - How helpful was the information you received?

2. Medicare has information about the quality of care that is delivered in different nursing homes and home health agencies. For example, information is available now about staffing levels in different nursing homes, the results of inspections, and information about such things as the number of bedsores that residents in different nursing homes have. Soon there will also be information available to the public about how different home health agencies are doing in terms of helping people get better or keeping them from getting worse. This information is (or soon will be) available about specific nursing homes and home health agencies in your area.

    - Did you know that this information was available? If so, how did you know?
    - As you think about what we've talked about today, is this information that would interest you? Why or why not?
    - Under what circumstances would it most interest you? *[Probe: What, when, where. Ask respondents to relate back to their own person experience or present a scenario/circumstance.]*
    - How would you use this information?
    - What would be the best way for you to get this information? *[Probe: T.V, Mail, Internet.]*

    - Specifically, what wording, format, and structure would attract you the most or raise your awareness about the information? What messages would get you to take action?

Thank you for your participation.

Moderator's Guide
Intermediary Audience

Dates: July 10 to July 19
Locations: Santa Barbara/Camarillo, CA; Providence, RI; and Boston, MA
Project: Describing Target Audiences for Facility Specific Quality Information Provided by Medicare

Note: The aim here is to trace the trajectory of functional decline in elderly and factors that trigger concern among adult children/caregivers, including people on Medicare that are a spouse/significant other to another person on Medicare, prior to acute episodes or crisis situations that require them to take immediate action. The point here is to find out when they begin to be concerned about their parent(s), spouse/significant other (and when, therefore, they might begin to be receptive to information that would help them plan), build on what we already know about what it is that prompts their concern (so that messages can be framed accordingly), and what other caregivers/intermediaries/sources of support/information they turn to at those times (so that these audiences can be identified and targeted).

A. Introduction and Warm-up

Thank you for coming. We appreciate your help.

My name is ___, and I work for an independent research and consulting firm. We've been hired by the agency that runs Medicare to help them understand how to get useful information to people who may be caring for an aging parent(s) or people on Medicare who is a spouse/significant other. In particular, Medicare is interested in getting people to think about the quality of care in different nursing homes or home health care agencies before they are in crisis situations, where they have to make decisions very quickly.

So, we want to get your thoughts, today, about the kinds of things that get caregivers, who you have assisted, (particularly, adult children of an aging parent(s) and spouses/significant others) thinking in advance about their parent(s) or spouses/significant others' needs, where they go for help or information, and what messages are most likely to get their attention and raise their awareness. For the purpose of today's discussion, the term caregiver, throughout the interviews will be defined as, "anyone, including the child/children of an aging parent(s) or a person on Medicare who is the spouse or significant other of a person on Medicare who is responsible for that persons health care needs and health care decisions.

Please be open and frank. We're not looking for "right" answers. We're recording these conversations, for research purposes, to make sure we capture everything that's said, but we will not use anyone's name or share this information beyond our research group. Also, some of our colleagues are observing behind the glass mirror.

We expect to be talking for about 2 hours. But if you need to get up to use the facilities, or whatever, please feel free to do so. Bathrooms are located ____________.

Any questions before we get started?

To start, I'd like you each to introduce yourselves (first name only), and tell us a little bit about the work that you do to provide support to caregivers and a little bit about the needs of the caregiver audience.

B. Interaction with caregivers

1. To what extent do you interact with caregivers (particularly, adult children of aging parent(s) or spouses/significant others of people on Medicare) in your work? *[Note: Put into context of the person's job position.]*
   - What sorts of concerns prompt them to come to you?
   - Do they come to you with specific needs, or questions, in mind – or do they come with generalized concerns?
     - What are those needs or concerns?
   - How would you characterize the caregivers who come to you? *Probe: age, gender, education, ethnicity, financial circumstances, living situation and if they are the child/children of aging parent(s), proximity to parent(s) (out of state?)*

2. In your experience, what are the kinds of things that are most likely to get caregivers, such as adult children or spouses/significant others, thinking *in advance* about their parent(s)'/spouses/significant other's needs? *Probe: financial worries? Functional decline? Specific events or behavioral problems? Recent visits? (e.g., for out of towners – around holiday times?)*

3. How savvy are the caregivers who come to you about the services that are available to dependent elders?
   - Of those who are savvy – where do they get their information?
   - How savvy are they about variations in the <u>quality</u> of services?

4. Do many caregivers appear to be actively "shopping," or searching, for alternatives?
   - Of those who do, what qualities are they looking for? *Probe: costs, proximity, breadth or depth of services, quality (clinical measures of quality or in terms of comfort, etc.)*
   - Apart from family and friends, where do people that seem to "shop" get their information?
   - Do you refer them to other sources of information?
   - If yes, where do you refer them for information? *Probe: What information do they already have available that they provide to caregivers?*
   - How would you characterize these shoppers, compared to the other caregivers who come to you?

C. Your work situation

1. When you are helping people plan or make arrangements for ongoing care needs, what are the most important factors that you need to take into account, in your professional role? *[Probe: need to avoid uncompensated days of care; availability of needed beds, services; quality]*

2. Is the quality of care provided in different home health agencies or nursing homes an important factor? How do you judge whether one nursing home or home health agency is better than another?

3. What information is available to you, in your professional role, about the quality of care that is delivered in different home health agencies or nursing homes?

4. Is information about quality provided through your workplace? Do you seek it out on your own?

5. If [better] comparative information about the quality of care were available to you, how likely would you be to use it in your job?

D. Medicare information

1. Do the caregivers who come to you actively look for Medicare information?
   - If so, what kind of information do they look for?

2. Whether or not they actively seek it, do you give them Medicare information?
   - What sort of information do you give them?
   - Where else do you send them for Medicare information?

3. Medicare has information about the quality of care that is delivered in different nursing homes and home health agencies.
   - Did you know that this information was available?
   - Have you ever referred clients to Medicare (or elsewhere) for this kind of information?
   - As you think about what we've talked about today, is this information that would interest your clients?
   - Under what circumstances would it most interest them?
   - What would be the best way for them to get this information?
   - What are the barriers to using the information that we have discussed? What about the information, if anything is would enable this audience(s) to use what is/may become available?

4. Medicare wants to get this information out to caregivers, so they can use it to make informed decisions for their dependent parent(s), spouses/significant others, and so they can be better

informed about what to look for in a nursing home or home health agency. For example, information is available about the number of pressure ulcers that nursing home residents have compared to other nursing homes. Soon there will be information available to the public about how a home health agency helps to either heal or improve wounds or is making them worse; or helps to improve a person's ability to feed himself/herself with less help. What kinds of messages about how to select and monitor care that comes from a nursing home or home health agency would get their attention, do you think?

- In particular, what kinds of messages would be most effective in getting them to think of these issues in advance, before they are in a crisis situation? Or, if they are not going to think of these issues in advance, what messages would raise their awareness about the availability of such information so when the time comes, they will be likely to use it?

Thank you for your participation.

APPENDIX B- SCREENERS

Screener to select Participants for 4-Person interviews
GENERAL CONSUMER

Please recruit to ensure 4 participants

Criteria:

- Men and Women **(Please recruit 3 women and 1 man or as close to 70% women and 30% men.)**
- Ages 45 – 64 and 65-75 **(If possible, recruit 1 person on Medicare that is a spouse between 65 & 75, 1 person that defines their lifestyle as active (For the purposes of this research this person should define an active lifestyle as someone who exercises several times a week, travels several times a year, or attends community activities or participates in community events several times a month, and 2 persons between the ages of 45 & 64 that are children of an aging parent(s) on Medicare.)**
- Participants who has an aging parent(s) that lives alone. **[Recruit 1.]**
- Participants whose family income is greater than $56, 500 per year.[1]
- Participants that meet the criteria in **bullet 2** & have done **one** of the following:
    - Arranged for funeral pre-planning for themselves or dependent family member;
    - Arranged for retirement savings beyond the traditional means of investing (e.g. through a 401K or IRA);
    - Purchased Long-Term Care insurance; or
    - Arranged Advanced Directives for themselves, family member, spouse, or significant other (e.g. Living Will, Durable Medical Power of Attorney, Health Care Proxy) **[If possible, recruit one respondent for each bullet listed.]**
- African Americans, Hispanics, Caucasians, and other ethnicities who read and speak English **(If possible, recruit 2 Hispanics, 1 African American and 1 Caucasian.)**
- Participants with an education level of 9th to 12th grade, a high school diploma, GED, Technical, Trade school, some college or graduate degree **[Recruit a mix.]**
- Participants **should not** currently work for the Federal Government.

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

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

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[1] Based on information from the University of California at Santa Barbara's Economic Forecast project, 1999 Median family income for Santa Barbara County. Median income for Boston is $74, 200 and Providence, RI $54, 100. Recruits for these sites will seek ranges that are lower than the median income so to ensure a mix of income levels for the research. The research team suggests recruiting participants whose income level is 25% that of the median income levels for these two sites. Boston, MA and Providence, RI income data was accessed from the Affordable Housing & community Development. Accessed on the website, http://www.efanniemae.com/hcd/single_family/ref_tools_info/hud_median_inc_limits.jhtml, on May 16th, 2002.

_______ Female
_______ Male

Please identify where you fall within the following age ranges?

______ Under 45 **[Thank respondent and end call.]**
______ Between 45 and 64 **[Go to question 2, but skip question 5.]**
______ Between 65 and 75 **[Go to question 2 and ask question 5 to these participants.]**
______ Over 75 **[Thank respondent and end call.]**

Do you currently (or have you ever) work(ed) for the Federal Government?

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

______ No **[If no, go to question 3.]**

Are you a spouse of a person on Medicare?

______ Yes **[Recruit 1 only.]**

______ No **[Go to question 3.]**

Are you the child of an aging parent(s)? **[If yes, ask if their aging parent lives alone and recruit 1 of these respondents.]**

______ Yes **[Recruit 2.]**

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

ONLY ASK THIS QUESTION IF PERSON IS IN THE AGE RANGE OF 65 to 75. Are you a person that:

_______ Exercises several times a week;

_______ Travels several times a year; or

_______ Attends community activities or participates in community events several times a month?

[Ask this question only of participants that are 65 and older. Recruit 1 who meets one or more of the criteria above.]

I am going to read you a list of activities and would like for you to tell me if you have done one of the following:

______ Arranged for funeral pre-planning for yourself or dependent family member;

______ Arranged for retirement savings beyond the traditional means of investing (e.g. through a 401K or IRA);

______ Purchased Long-Term Care insurance for yourself; or

______ Arranged Advanced Directives for yourself, family member, spouse, or significant other (e.g. Living Will, Durable Medical Power of Attorney, Health Care Proxy)

________ None of the above **[Thank respondent and end call.]**

Please stop me when I read the range that includes your total household annual income.

________ Less than or equal to $56,500 **[Thank respondent and end call.]**

________ Greater than $56,500 **[Go to question 8.]**

What is your race or ethnicity? **[Do not read answers. Please seek a mix.]**

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

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

____ 9th grade or less **[Thank respondent and end call.]**
____ 9th – 12th grade **[Go to invitation.]**
____ High School Diploma or GED, Technical or Trade School **[Go to invitation.]**
____ Some College **[Go to invitation.]**
____ College Graduate, Graduate School **[Go to invitation.]**

Invitation:

Thank you for answering my questions. You are eligible to participate in the individual interview about health care quality information. It will last about one and a half to [two] hours and you will be paid $75 for your time. Your experience and opinions are very important to us. During the discussion we will be speaking in English and reading some print materials, so it is very important that you are comfortable speaking and reading English. Are you comfortable speaking and reading English?

☐ Yes
☐ No **[Thank respondent and end call.]**

The interview will be held on ________ at __________________________.

Can you attend?
________ Yes
________ No **[Thank respondent for their time and end call.]**

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

____

Thank you.

Screener to select Participants for Group 2, Three-Person interviews
FORMAL INTERMEDIARIES

Please recruit to ensure 6 participants

Criteria:

- Men and Women **(Please recruit as close to 70% women and 30% men.)**
- Participants who work with caregiver(s) **[Child/Children of an aging parent, spouse, or significant other.]**
- Participants who work as one of the following:
  - Coordinator of a Caregiver Group or Person that has lead a Caregiver Support Group Seminar;
  - Hospital Discharge Planner or Case Manager, or Hospital-based Social Worker
  - Nursing Home Admissions Counselor or Continuing Care/Retirement Community Admissions Counselor, or Daycare Admissions Counselor;
  - Patient Care Coordinator of a Home Health Care Agency;
  - Coordinator of Geriatric Assessment Program or Geriatric Evaluation Services; **[Recruit through Department of Health.]**
  - Doctor's office employee that provides counseling and/or referrals for nursing home or home health care placement;
  - State Health Insurance Counselor (SHIP) Counselor
  - Large local employer (Human Resources/Office of Personnel Management); or
  - AARP (American Association of Retired Persons) volunteer that counsels caregivers. **[Recruit NO MORE THAN ONE from every job position up to 6.]If unable to recruit participants from all categories from above criteria, recruit one physician, a Geriatrician or Internal Medicine physician, whose patient volume are 75% people on Medicare.**
- African Americans, Hispanics, Caucasians, and other ethnicities who read and speak English **[Recruit a mix.]**
- Participants **should not** currently work for the Federal Government.

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

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

_______ Female
_______ Male

Do you currently (or have you ever) work(ed) for the Federal Government ?

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

______ No **[If no, go to question 2.]**

Please tell me which job title best describes your position: **[Recruit one respondent from each category if possible, up to 6.]**

______ Coordinator of a Caregiver Group or Person that has lead a Caregiver Support Group Seminar

_____ Hospital Discharge Planner or Case Manager, or Hospital-based social worker

_____ Nursing Home Admissions Counselor or Continuing Care/Retirement Community Admissions Counselor, or Daycare Admissions Counselor

_____ Patient Care Coordinator of a Home Health Care Agency

_____ Coordinator of Geriatric Assessment Program or Geriatric Evaluation Services **[Recruit through Department of Health.]**

______ Doctor's office employee that provides counseling and/or referrals for nursing home or home health care placement

______ State Health Insurance Counselor (SHIP) Counselor

_____ Large local employer **[Please recruit through the Human Resources Department or Office of Personnel Management the person who is in charge of general information and/or support programs around dependent care (for a nursing home or home health care agency) for employees. For the first site visit, recruit from UC Santa Barbara, SBRC, Raytheon, Applied Magnetics, or Goleta Valley Cottage Hospital]**; or

_____ AARP (American Association of Retired Persons) volunteer that counsels caregivers

_____ None of the above **[Thank respondent and end call.]**

_______If unable to recruit participants from all categories from above criteria, recruit one physician , a Geriatrician or Internal Medicine, whose patient volume is 75% people on Medicare and ask;

Are you either an Internal Medicine physician or Geriatrician?

_____ Yes **[Go to next question.]**

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

How would you describe your patient volume of persons age 65 and older? **[Read answers.]**

_____ Less than 75% **[Thank respondent and end call.]**

_____ 75% or greater **[Recruit one in place of criteria missed in Question 2.]**

Do you work and come into contact with or work with caregivers (defined as persons responsible for helping to take care of an elderly person on Medicare), either children or a child of an aging parent or spouses/significant others?

______ Yes

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

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

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

Invitation:

Thank you for answering my questions. You are eligible to participate in the individual interview about quality health care information. It will last about one and a half to [two] hours and you will be paid $100 for your time. NOTE: If a physician recruit, will pay $150. Your experience and opinions are very important to us. During the discussion we will be speaking in English and reading some print materials, so it is very important that you are comfortable speaking and reading English. Are you comfortable speaking and reading English?

☐ Yes
☐ No **[Thank respondent and end call.]**

The interview will be held on ________ at __________________________.

Can you attend?

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

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

____

____

Thank you.

Screener to select Participants for 4-Person interview
Caregivers

Please recruit to ensure 4 participants

Criteria:

- Men and Women **(Please recruit 3 women and 1 man or as close to 70% women and 30% men.)**
- Ages 45 – 64 and 65-75 **(If possible, recruit 2 people on Medicare that are spouses or significant others between 65 & 75 and 2 persons between the ages of 45 & 64 that are responsible for the health care decisions and health care needs of a person on Medicare.)**
- Participants who have attended a support group or have attended seminar about caring for the elderly, but are not in the process of choosing a nursing home for a family member, spouse, or loved one, but anticipate the need to within the next 6 months to 1 year, or have had some home health care 2 to 5 times a week in the past year.
- Participants who have contacted respite services, daycare services, or have had someone come into the home to provide respite care. **[If possible, recruit 2.]**
- Participants whose family income is greater than $56, 500 per year.[1]
- African Americans, Hispanics, Caucasians, and other ethnicities who read and speak English **(If possible, recruit 2 Hispanics, 1 African American and 1 Caucasian.)**
- Participants with a high school diploma, GED, Technical, Trade school, some college or graduate degree**. [Seek a mix.]**
- Participants **should not** currently work for the Federal Government.

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

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

_______ Female
_______ Male

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[1] Based on information from the University of California at Santa Barbara's Economic Forecast project, 1999 Median family income for Santa Barbara County. Median income for Boston is $74, 200 and Providence, RI $54, 100. Recruits for these sites will seek ranges that are lower than the median income so to ensure a mix of income levels for the research. The research team suggests recruiting participants whose income level is 25% that of the median income levels for these two sites. Boston, MA and Providence, RI income data was accessed from the Affordable Housing & Community Development. Accessed on the website, http://www.efanniemae.com/hcd/single_family/ref_tools_info/hud_median_inc_limits.jhtml, on May 16th, 2002.

Please identify where you fall within the following age ranges?

______ Under 45 **[Thank respondent and end call.]**
______ Between 45 and 64
______ Between 65 and 70
______ Over 70 **[Thank respondent and end call.]**

Are you responsible for helping to take care of an elderly person on Medicare?

______ Yes **[If yes, go to question 3.]**

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

Do you currently (or have you ever) work(ed) for the Federal Government?

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

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

Have you ever attended a support group or seminar about taking care of the elderly?

_______ No **[Go to question 6.]**

_______ Yes **[Go to question 7.]**

Do you anticipate having to make a placement for your family member/spouse/loved one in a nursing home within the next 6 months to 1 year ORr have you had home health care provided to this person 2 to 5 times a week within this time frame of 6 months to 1 year?

_______ Yes to either situation **[Go to question 7.]**

_______ No **[Go to question 6.]**

Have you contacted respite services daycare services, or has someone come into your home to provide respite care for your family member/spouse/loved one?

________ Yes to any of the situations **[Go to question 7.]**

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

Please stop me when I read the range that includes your total household annual income.

________ Less than or equal to $56,500 **[Thank respondent and end call.]**

________Greater than $56,500 **[Go to question 8.]**

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

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

What was the last grade you completed?

____ 9th grade or less **[Thank respondent and end call.]**
____ 9th – 12th grade **[Go to invitation.**
____ High School Diploma or GED, Technical or Trade School **[Go to invitation.]**
____ Some College **[Go to invitation.]**
____ College Graduate, Graduate School **[Go to invitation.]**

Invitation:

Thank you for answering my questions. You are eligible to participate in the individual interview about health care information. It will last about one and a half to [two] hours and you will be paid $75 for your time. Your experience and opinions are very important to us. During the discussion we will be speaking in English and reading some print materials, so it is very important that you are comfortable speaking and reading English. Are you comfortable speaking and reading English?

☐ Yes
☐ No **[Thank respondent and end call.]**

The interview will be held on ________ at __________________________.

Can you attend?
________ Yes
________ No **[Thank respondent for their time and end call.]**

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

____

____

Thank you.

APPENDIX C- RESPONDENT DEMOGRAPHICS

Respondent Demographics

Caregiver Audience

Site & Respondents' Initials	Age Range	Gender	Race	Qualifying Response
Camarillo, CA				
KS	45-64	Female	Caucasian	Attended Caregiver Support Group
SH	45-64	Female	Caucasian	Anticipate Placement & Contacted Respite Services
FC	45-64	Male	Caucasian	Attended Caregiver Support Group & Anticipate Placement
FR	65-75	Female	Caucasian	Contacted Respite Services
Providence, RI				
LF	45-64	Female	Caucasian	Attended Caregiver Support Group & Contacted Respite Services
AY	65-75	Female	Caucasian	Anticipate Placement
CL	45- 64	Female	Caucasian	Attended Caregiver Support Group & Contacted Respite Services
YR	65-70	Female	Caucasian	Attended Caregiver Support Group & Contacted Respite Services
RM	65-70	Female	Caucasian	Attended Caregiver Support Group
RM	65-75	Male	Caucasian	Anticipate Placement into Home Health Care
Boston, MA				
BN	45-64	Male	Caucasian	Attended Caregiver Support Group & Anticipate Placement
JT	45-64	Female	Caucasian	Contacted Respite

				Services
SE	45-64	Female	Caucasian	Anticipate Placement
MQ	45-64	Female	Caucasian	Contacted Respite Services

General Consumer Audience

Site & Respondents' Initials	Age Range	Gender	Race	Qualifying Response
Camarillo, CA				
PW	45-64	Male	Asian American	Retirement Savings
MW	65-75	Female	Caucasian	Active Lifestyle; Pre-funeral Plan; Retirement Savings; Advance Directives; Long-term Care Insurance
CF	45-64	Female	Mexican American	Pre-funeral Plan
DL	65-75	Female	Caucasian	Pre-funeral Plan & Advance Directives
Providence, RI				
MD	45-64	Female	Caucasian	Purchase Long-Term Care Insurance; Pre-funeral Plan; Advance Directives
DW	45-64	Female	African American	Active Lifestyle; Pre-funeral Plan
CR	65-75	Female	Caucasian	Retirement Savings; Pre-funeral Plan
TU	65-75	Male	Caucasian	Pre-funeral Plan & Retirement Savings
BF	65-75	Male	Caucasian	Pre-funeral Plan & Retirement Savings
Boston, MA				
MS	45-64	Female	Caucasian	Retirement Savings; Advance Directives
JL	45-64	Female	Caucasian	Pre-funeral Plan; Retirement Savings; Advance Directives

AS	45-64	Female	Caucasian	Pre-funeral Plan; Retirement Savings; Advance Directives
WM	45-64	Female	Caucasian	Pre-funeral Plan; Long-Term Care Insurance; Retirement Savings
MW	65-75	Female	African American	Retirement Savings
LL	65-75	Male	Caucasian	Active Lifestyle; Pre-funeral Plan; Long-Term Care Insurance; Retirement Savings

Intermediary Audience

Site & Respondents' Initials	Race	Job Position
Camarillo, CA		
LF	Caucasian	Patient Care Coordinator
HB	Caucasian	Hospital Discharge Planner
KR	Native American	SHIP Counselor
BG	Hispanic	AARP Volunteer
RT	Caucasian	Caregiver Group Coordinator
HF	Caucasian	Continuing Care Admissions Counselor
MP	Caucasian	Patient Care Coordinator
CW	Caucasian	Doctor's Office Employee
Providence, RI		
PT	Caucasian	Caregiver Group Coordinator
EF	Caucasian	SHIP Counselor
DC	Caucasian	Doctor's Office Employee
RP	Caucasian	Large Local Employer- Human Resources
TT	Caucasian	Large Local Employer- Human Resources
CP	Caucasian	Nursing Home Admissions Counselor
ER	Caucasian	Hospital Discharge Planner
BF	Caucasian	Nursing Home Admissions Counselor
Boston, MA		
KM	African American	Case Manager
JL	African American	Caregiver Group Coordinator
JR	Caucasian	Resource Coordinator- Large Local Employer
DF	Caucasian	Nursing Home Admissions Counselor
CM	Caucasian	Case Manager

Caregiver Audience

Qualifying Answer	**Number of Respondents**
Attended Caregiver Support	1
Anticipated Placement into a Nursing Home or Home Health Care Agency and Contacted Respite Services	1
Attended a Caregiver Support Group meeting and/or seminar and Anticipated Placement into a Nursing Home or Home Health Care Agency	3
Contacted Respite Services	3
Attended a Caregiver Support Group meeting and/or seminar and Contacted Respite Services	3
Anticipate Placement into a Nursing Home or Home Health Care Agency	3
TOTAL NUMBER OF RESPONDENTS	**14**

General Consumers

Qualifying Answer	Number of Respondents
Retirement Savings	2
Active Lifestyle, Pre-funeral Plan, Retirement Savings, Advance Directives, and Long-Term Care Insurance	1
Pre-funeral Plan	1
Pre-funeral Plan and Advance Directives	1
Long-Term Care Insurance, Pre-funeral Plan, and Advance Directives	1
Active Lifestyle and Pre-funeral Plan	1
Retirement Savings and Pre-funeral Plan	3
Retirement Savings and Advance Directives	1
Pre-funeral Plan, Retirement Savings, and Advance Directives	1
Pre-funeral Plan, Retirement Savings, and Advance Directives	1
Pre-funeral Plan, Long-Term Care Insurances, Retirement Savings	1
Pre-funeral Plan, Active Lifestyle, Long-Term Care Insurance, and Retirement Savings	1
TOTAL NUMBER OF RESPONDENTS	**15**

Formal Intermediaries

Job/Position Held	**Number of Respondents**
SHIP Counselor	2
AARP Volunteer	1
Human Resources employee from Large, local employer	3
Hospital D/C Planner/Case Manager	4
Coordinator of Caregiver Support Group	3
Doctor’s office employee that provides referrals	2
Home Health Care Counselor/Patient Care Coordinator	2
Nursing Home Admissions Counselor/Continuing Care Admissions Counselor	4
TOTAL NUMBER OF RESPONDENTS	**21**