

# **Nursing Home Consumer Choice Campaign Needs Assessment Report**

## **Final Report**

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Submitted to:

Annette Lang and Chris Koepke  
Centers for Medicare & Medicaid Services  
7500 Security Boulevard  
Baltimore, MD 21244-1850

Prepared by:

Barents Group of KPMG Consulting, Inc.  
1676 International Drive  
McLean, VA 22102-4828

Under subcontract to:

Ketchum  
2000 L Street, NW  
Washington, DC 20036

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# NURSING HOME CONSUMER CHOICE CAMPAIGN NEEDS ASSESSMENT REPORT



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## EXECUTIVE SUMMARY

### Introduction

In an effort to improve the quality of care in nursing homes, the Centers for Medicare & Medicaid Services (CMS) has implemented a multi-year program highlighting areas important to both nursing home residents and providers. In order to raise awareness of these quality improvement efforts, and to increase consumers demand for nursing home information, CMS is expanding the scope of existing efforts and launching a consumer awareness campaign, known as the Consumer Choice Campaign for Quality Care.

The purpose of the Consumer Choice Campaign for Quality Care is to provide consumers with information about the performance of nursing homes in order to help them make better informed decisions. CMS has proposed a list of nursing home performance measures drawn from the Minimum Data Set (MDS) to be publicly reported for the campaign.

The Barents Group of KPMG Consulting, Inc. (Barents) conducted comprehensive needs assessment research for CMS's Consumer Choice Campaign in the winter of 2001-02, seeking to address the central research question of how CMS can motivate consumers to use nursing home quality information to make better informed decisions. Within the context of this question, Barents developed objectives to identify the campaign's target audience and map the audience's decision-making environment to ultimately understand their motivations for using nursing home quality information.

### Research Methods

- ◆ Literature review
- ◆ Nine focus groups with family caregivers, doctors, and hospital discharge planners
- ◆ Thirty-eight key informant interviews with community organizations, Quality Improvement Organizations, hospital discharge planners, nursing home associations, and other stakeholders

### Key Findings

- ◆ The primary audience for the nursing home performance information is family caregivers.
- ◆ Consumers view quality differently from CMS's proposed clinical performance measures. Most caregivers evaluate nursing homes on the basis of cleanliness, caring, and staffing at times taking the quality of clinical care for granted.
- ◆ Consumers are not likely to use clinical quality indicators in isolation to make decisions. They also factor in information about cost, services, location, availability, as well as their own perceptions of quality.
- ◆ CMS's proposed performance measures may be perceived by consumers as negative and frightening.

- ◆ 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. Other factors that discourage caregivers from seeking out nursing home information include:
  - ◇ Perceived lack of nursing home choice
  - ◇ Family pressure and conflict
  - ◇ An overwhelming decision-making process.
- ◆ Key caregiver influencers include hospital discharge planners, physicians, consumer groups and community organizations, and the media.
- ◆ Doctors and discharge planners are willing to refer consumers to information about nursing home performance, but are concerned about the liability in recommending specific facilities. Additionally, due to heavy caseloads, doctors and discharge planners often face time constraints in counseling caregivers and patients.

### **Opportunities**

- ◆ There is caregiver demand for nursing home quality information as well as the motivation to use it. Caregivers are highly concerned about the quality of care in nursing homes, and family caregivers want to ensure that they choose the best facility for their loved one.
- ◆ Caregivers, if placing a loved one in a nursing home directly from a hospital, can be an easily identifiable and easily located target audience because of the likelihood that they will interface with hospital discharge planners.
- ◆ Hospital discharge planners and physicians are willing intermediaries for nursing home quality information, even if limited in certain capacities.

### **Barriers and Challenges**

- ◆ There is a disconnect between CMS's proposed performance measures and consumer perceptions of nursing home quality.
- ◆ Caregivers may have negative associations with proposed performance measures.
- ◆ The "problem-focus" of performance measures may create an adversarial relationship with providers and the nursing home industry as well as raise concerns regarding increased litigation against nursing homes.
- ◆ Campaign efforts may overlap with state and private efforts to provide nursing home information.
- ◆ There are concerns about reliability of MDS data and the proposed performance measures among physicians, discharge planners, and to some extent, the nursing home industry.
- ◆ Many consumers have limited or no choice of nursing homes due to factors such as cost, location and availability. Therefore, for some members of the target audience, the use of quality information to select a nursing home would not be relevant.

## Preliminary Conclusions

- ◆ Caregivers are the primary audience for CMS's consumer choice campaign and may be motivated to use nursing home quality information if:
  - ◇ Caregivers are educated on the connection between quality of care and quality of life
  - ◇ Nursing home quality information is positioned to help caregivers with the problems of guilt, stigma, fear of the unknown, lack of control, and family pressure and conflict.
  - ◇ Nursing home quality information can be seen as addressing caregivers' central concern of securing and maintaining a safe, caring and comfortable nursing home placement for their loved ones.
- ◆ Discharge planners are key caregiver influencers, in addition to doctors/nurses, consumer groups and community-based organizations, and media. Mapping of the decision-making process has suggested that consumers desire and use nursing home quality information primarily at the time they are making nursing home decisions and rely on intermediaries to help them access needed information. CMS may consider:
  - ◇ Educating discharge planners on quality
  - ◇ Providing discharge planners with one to two-page handouts for patients/families discussing nursing home quality.
  - ◇ Utilize other channels in supporting a main discharge planner strategy. The channels include physicians who may intervene prior to a crisis point by educating caregivers about nursing home placement and quality; organizations such as the Alzheimer's Association who have vested interest and strong experience in counseling caregivers; and media to inform the professional and general public of the existence of CMS's new quality measures.
- ◆ Stakeholders are looking to CMS to work collaboratively to position nursing home performance information in a positive rather than punitive manner. Consumers as well as industry representatives are interested in CMS intentions to improve the quality of care. CMS can address stakeholder concerns by:
  - ◇ Better communicating with stakeholders about the quality initiative and inviting their input into the strategy development for a national campaign.
  - ◇ Publicly positioning the quality initiative as a proactive process of helping the industry ensure the best possible care for nursing home residents.
  - ◇ Continuing to support behind the scenes efforts to develop and maintain the quality measurement and improvement infrastructure.

## INTRODUCTION

In an effort to improve the quality of care in nursing homes, the Centers for Medicare & Medicaid Services (CMS) has implemented a multi-year program highlighting areas important to both nursing home residents and providers. In order to raise awareness of these quality improvement efforts, and to increase consumers demand for nursing home information, CMS is expanding the scope of existing efforts and launching a consumer awareness campaign, known as the Consumer Choice Campaign for Quality Care.

The purpose of the Consumer Choice Campaign for Quality Care is to provide consumers with information about the performance of nursing homes in order to help them make better informed decisions. CMS has proposed a list of nursing home performance measures drawn from the Minimum Data Set (MDS) to be publicly reported for the campaign (see Appendix II for measures).

The Barents Group of KPMG Consulting, Inc. (Barents) conducted comprehensive needs assessment research for CMS's Consumer Choice Campaign in the winter of 2001-02, seeking to address the central research question of how CMS can motivate consumers to use nursing home quality information to make better informed decisions. Within the context of this question, Barents developed objectives to identify the campaign's target audience and map the audience's decision-making environment to ultimately understand their motivations for using nursing home quality information. Description of the research and research findings are presented in this report.

## METHODS

This report synthesizes and summarizes findings across the three methodologies Barents employed in the needs assessment research. Methodologies are described below and included a literature review; key informant interviews; and focus groups with consumers, hospital discharge planners, and physicians.

### Review of Literature

Barents reviewed the available literature on nursing home performance measures by performing a search of the PubMed database, referring to publication bibliographies, and reviewing previous studies conducted for CMS describing the selection of the nursing home performance measures. Search terms used with PubMed were: “nursing home,” “quality,” “long term care,” “decision-making,” and “performance indicators.” To gain a better understanding of trends impacting nursing homes, researchers examined data from the 2000 Census, the National Nursing Home Survey, and the 1997 State Data Book on Long Term Care Program and Market Characteristics. Finally, Barents also explored the content of websites that currently provide information about nursing home performance in order to obtain a sense of the existing information environment.

### Key Informant Interviews

Barents completed 38 semi-structured “key informant” telephone interviews to obtain expert input and advice on the issues surrounding nursing home quality information and its communication to consumers. With CMS guidance, Barents generated a list of target stakeholder groups including: hospital discharge planners, physicians, hospitals, Quality Improvement Organizations (QIOs), Area Agencies on Aging, State Nursing Home Ombudsmen, state departments on aging, consumer advocacy groups, senior information providers, community-based service organizations, minority organizations, professional associations, trade associations, nursing home industry experts, policy experts, and academics. (See Appendix II for complete list). Representatives from the various groups were contacted and invited to participate in half-hour to hour long telephone interviews with research staff. Concurrently, Ketchum team members contacted members of the healthcare media and conducted similar interviews with two representatives.

The stakeholder interviews were divided into two general categories: those with direct-service providers and those with non-direct service providers. Separate interview protocols were created for the two sets of stakeholders to better tap specific areas of expertise, though the lines of questioning in each protocol were generally parallel. (See Appendices III, IV, and V for list of interview participants and protocols.)

Interview questions focused on the following topics: audiences for nursing home quality information; information needs of various audiences; current levels of awareness and varying definitions of nursing home quality; current sources of nursing home quality information; and strategies and advice for communicating about nursing home quality.

## Focus Groups

Barents conducted a total of nine focus groups in Baltimore, Maryland and Tampa, Florida. Six groups were held with family caregivers (comprised of persons who had placed a loved one in a nursing home in the last year, and those who anticipated placing a loved one in a nursing home in the next year), two groups with hospital discharge planners, and one with physicians. (See Appendices VI through IX for chart of focus group participants and moderator guides.)

### *Caregivers*

Participants were diverse in terms of age, (ranging from 30-60 years), sex, and race. Barents conducted two groups with African-American participants, and seven general groups comprised of white, African-American, Hispanic, and Asian participants. Participants' descriptions of their nursing home choices also indicated a wide representation of income levels, with some able to finance more expensive private facilities, and others relying on Medicaid reimbursement.

The moderator asked respondents to use their own experiences to map out the timeline and process of selecting a nursing home, and solicited feedback on definitions and perceptions of nursing home quality, sources of information on quality, the benefit of quality information to consumers, opportunities, barriers and challenges to consumer use of quality information, and reactions to proposed nursing home performance measures.

### *Discharge Planners*

Participants were employed by different area hospitals and had a mix of nursing and social work backgrounds.

The moderator asked respondents about their roles in hospitals, the process of hospital discharge into nursing facilities, nursing home quality information they currently use, their reactions to proposed quality measures, and the benefit of quality information to themselves as well as patients and families.

### *Physicians*

Participants were internists and family practitioners with at least five years of experience caring for elderly patients. Number of years in practice, number of patients placed in nursing homes, and amount of time spent attending to patients in hospitals varied by participant.

The moderator asked about the physician's role in helping families place loved ones in nursing homes, their comfort level with providing quality information to patients and families, and their reactions to the proposed quality measures.

## RESEARCH FINDINGS

In addressing the question of how CMS can motivate consumers to use nursing home quality information to make informed decisions, Barents framed research activities around identifying the target audience and understanding their challenges, and mapping the target audience's decision-making environment.

### **Audience**

Findings from the research suggest that family caregivers, particularly spouses and adult children (Jenkins, 2000), are the most appropriate audience for information about nursing home performance, since they generally make nursing home placement decisions. Individuals admitted to nursing homes frequently suffer from severe health problems and/or cognitive impairments that limit their ability to make decisions independently (Tynchuk, et al, 1988).

#### *Caregiver Characteristics*

Statistics posted on the National Family Caregivers Association (NFCA) website provide a general sense of the target population and the issues it encounters. Currently, 59 percent of the adult population either cares for or expects to care for an elderly relative, such as a spouse or parent (NFCA, 2000), and the GAO estimates that family caregivers provide roughly 80% of all home care services (U.S. General Accounting Office, 1994). While generally perceived of as an issue affecting women, 44% of caregivers are now men (NFCA, 2000). According to NFCA, 61% of "intense" family caregivers, or those who provide at least 21 hours of care to loved ones per week, suffer from depression. The NFCA also estimates that primary caregivers, particularly spouses, do not receive consistent aid from other family members, and that up to three of four such caregivers shoulder the burden alone (NFCA and Fortis Long Term Care, 1998).

Characteristics of the nursing home population can also be reflective of the caregiver audience. Nursing home residents comprise a relatively homogenous population. In 1997, about 75 percent of nursing home residents were women, 90 percent of residents were white, and 51 percent were 85 years or older (Sayhoun et al., 2001). Between 1985 and 1997 there was a small increase in the proportion of African American residents in nursing homes from 6% to 10%. The literature has suggested that low nursing home utilization rates for non-whites and Hispanics/Latinos may be attributable to a combination of traditional family values and financial constraints (Angel et al., 1996).

#### *Caregiver Challenges*

Caregivers face a number of challenges when choosing a nursing home for a loved one that can make the process a harrowing event. For most caregiver focus groups respondents, the experience was highly stressful and unpleasant, describing it as "scary," "sad," and "depressing." Many caregivers reported feeling overwhelmed by the process, and feeling constantly worried, drained, and hurried. One lamented that "it's bad when you don't have much notice [to make a decision], and with the pressures of discharge and insurance, you feel so rushed." As one nursing home ombudsman summarized, "it breaks the family's heart to admit their loved one in a nursing home."

The most pervasive and commonly mentioned emotional challenge to caregivers when making a nursing home placement decision was guilt. The feeling seemed to stem from the caregiver's personal values and desires to keep the loved one in the family home rather than in a nursing home, and was often compounded by resistance from other family members and especially from the loved ones themselves. One caregiver in the focus groups referred to her experience with admitting her mother into a nursing home. "The older generation doesn't understand. They say, 'We took care of you, why won't you take care of us? You don't love me anymore?'" Another caregiver giving her perspective said, "it feels like I'm letting them [loved ones] down -- I just don't want them to be in a nursing home."

Many caregivers mentioned feeling not only personal guilt and shame, but also social pressure to care for loved ones at home or to pay for home care. Participants spoke of the stigma surrounding the decision to put a family member in a nursing home. One caregiver expressed that she did "not necessarily want to let other people know about it" while another remarked that "people think you are throwing them [your parents] away."

According to caregivers and experts, negative feelings such as guilt and shame associated with making a nursing home placement can inhibit or delay family caregivers from seeking out information about nursing homes or from planning earlier for nursing home admission. One caregiver explained that "you don't even think about it until you can't handle it anymore. I thought, 'I'll know when the time's right, then I'll deal with it.' Probably wait until crisis time."

Fear of the unknown, confusion, and feelings of powerlessness could also hamper the decision-making process for many of the caregivers in the focus groups who described their experiences:

- ◆ "You just don't know what's good and bad."
- ◆ "I just didn't want to think about it. You just think about horror stories."
- ◆ "You hear so much bad, it makes it hard to choose."
- ◆ "Did I do the right thing? There's no way I can know for sure."
- ◆ "It was the hospital's decision. I didn't feel I had a choice."
- ◆ "When the hospital discharged him, it seemed like they turned him over to die."
- ◆ "The [nursing home] director called up and said 'the home has a bed open and if you don't take it now, I can't guarantee when another one will open.' And you just have to give in to them."
- ◆ "It was such an emotional thing and I was flying all over the place. There was so much chaos with people saying different things, it made it hard to do any definitive research...."

A previous study of family caregivers also indicated that self-doubt among the audience is common. It found that all participants in the research experienced "intense self-questioning in response to the [nursing home] placement. They wondered whether they had done the right thing and whether there was anything they could have done to avert the need for nursing home care" (Rodgers, 1997).

However in many cases, many caregivers also reported a sense of relief when a loved one's doctor or discharge planner initiated the discussion on a nursing home admission. When asked what would make it easier for caregivers to begin considering nursing homes for their loved ones, several mentioned that compelling medical reasons raised by professionals would help because they seemed to legitimize the placement decision while relieving some of the guilt that accompanies a decision solely made by the family. One caregiver said in regard to a nursing home placement for her loved ones that ideally "it would be the hospital doing it, instead of putting them in the car from [my] home." Other caregivers shared the sense that "if there was a medical reason, then I would think about it," and felt that the start of the process could be facilitated if "the physician could bring it up, start the discussion, and talk about reality."

While guilt and associated social stigma were pervasive themes in most caregiver experiences, the effects appeared to be mitigated when caregivers felt they had done their best for their loved ones. Caregivers in the focus groups who reported feeling no guilt in placing a loved one in a nursing home also expressed confidence that they had done all they could have done for their loved ones. One commented, "you don't feel guilt if you don't have a choice – you have to [go to] work and live your life." Furthermore, when asked about the greatest issue caregivers hoped could be resolved in the nursing home decision-making process, caregivers repeatedly mentioned "guilt."

#### *Caregiver Perceptions of Nursing Home Quality*

In caregiver focus groups, moderators asked participants to write down words they associated with "nursing home quality." Responses generally concerned matters affecting a resident's quality of life rather than clinical indicators. The most commonly mentioned concepts of nursing home quality were:

- ◆ Cleanliness: A clean environment was extremely important to caregivers. The "smell test" and odors were repeatedly mentioned in caregiver focus groups as potential "warning signs" of neglect and poor quality of care.
- ◆ Caring: Caregivers placed great emphasis on the interpersonal aspects of care, such as treating the residents with kindness, respect, and dignity. As one participant related, "the first thing that pops into our heads is 'caring' because we care, not just medically, but emotionally."
- ◆ Staffing: Patient-staff ratio and staff qualifications figured prominently in consumer perceptions of nursing home quality. Participants frequently attributed poor quality of care to inadequate staffing and staff training, high turnover, low-pay for workers, and "indifferent orderlies." One caregiver asked, "who in the world would want to be an orderly for one of those things?" and added, "no one cares, that's the scary thing."
- ◆ Customer satisfaction: Caregivers often relied on "word-of-mouth" evidence from friends and acquaintances who had relatives in local facilities or had extensive professional experience in the field to evaluate the quality of care in area nursing homes.

Other common perceptions of nursing home quality in caregiver focus groups included a “safe and secure environment,” facility licensure or accreditation, and the availability of stimulating activities or hot meals that would enhance a resident’s quality of life.

Finally, there was a tendency among caregivers to associate nursing homes with lack of quality as well as other negative concepts. Caregiver focus group participants offered forth such terms as “neglect,” “abuse,” “gloomy,” “depressing,” and often referred to horror stories they had encountered in the media. Many associated the nursing home with death, one calling it “the house of death,” and another describing it as “where you go to wait to die.”

Caregivers in the focus groups seemed to believe that quality of care can vary greatly among nursing homes, ranging from horrible to excellent, and at times suggesting a relationship between the quality and cost of care. Additionally, most believed that the quality could also be variable within a given facility, contingent upon how often family and caregivers visited a resident and how closely they themselves monitored the care received. One caregiver advised, “that’s the whole key to nursing home care – make yourself visible. If you do not show that you’re paying attention, they’ll (loved ones) be set to the side. You have to know to be vigilant. It’s really sad.” Another mentioned that “once they [staff] realize you’re around, they’re nicer and they [loved ones] get better quality of care.” Many, however, feared retaliation for monitoring care. “With her bed sores, I literally screamed one time, but do they take it out on my mom when I’m not there?” Another caregiver shared her experience saying “we brought up quality problems, and it made it worse for him.”

Most caregiver participants in focus groups were loath to consider moving a resident to another facility after initial placement and did not feel that they would be inclined to use nursing home quality information towards that particular end. With regard to changing facilities, one participant related, “then you create another decision-making hassle and more anguish.”

#### *Knowledge of Available Information Sources*

The literature review conducted for this project revealed that there is a large amount of information on nursing home performance already publicly available in various electronic and print forms. Nursing Home Compare on [www.medicare.gov](http://www.medicare.gov) provides information on staffing, resident characteristics, and performance on a variety of clinical metrics, and many state departments of health display nursing home inspection results on their websites. Commercial companies, such as [carescout.com](http://carescout.com), sell specialized reports on nursing home performance that synthesize data from OSCAR and state inspections, the Joint Commission for the Accreditation of Healthcare Organizations publishes the data they use for accreditation purposes, and consumer groups provide nursing home checklists, inspection results, and complaint data. There are even litigation lawyers that present information about nursing home complaints on their websites in an attempt to attract customers. However, while there is an abundance of nursing home information currently available, focus group results indicated that few caregivers are aware of it.

#### *Caregiver Perceptions of the Proposed Performance Measures*

During the focus groups, caregivers were also presented with CMS’s proposed performance indicators from the MDS to which participants had mixed reactions. Many felt the measures had

negative connotations, with some responding by shaking their heads, making sounds of distaste and remarking that “they’re all the things you think of that people are complaining about,” and “these are all widespread problems in nursing homes.” One participant commented that looking at the measures “makes you want to crawl back into the shell.” Interestingly, discharge planners and physicians in focus groups had similar concerns regarding the performance measures. “A family can look at something like this and it all looks horrible.”

While other caregiver focus group participants were less fearful of the measures, many also found them less personally relevant believing that “it doesn’t quite make sense if they don’t have anything about friendly staff,” “quality is more than this,” and “in a way, these [measures] aren’t comprehensive.” Furthermore, finding some of the measures incongruous, one caregiver remarked, “you don’t think of a loved one as improving when they go into a nursing home.” Some participants seemed to take the quality of clinical care in nursing homes for granted. These individuals paid more attention to activities and quality of life for residents because they did not feel they needed to be concerned about the clinical aspect of care. Still others expressed reservations at the potential for the manipulation of data and asked specifically how the measures were reported. “You can always play with research and play with results.”

Though many of the caregiver reactions to the proposed performance measures were negative, some also saw opportunities in having access to the information. Some viewed them as potential questions to ask of nursing homes or as ways to narrow down an initial list of facilities to research. As mentioned previously, many caregivers believed that monitoring care after placement in a nursing home was critical in ensuring quality treatment for a loved one, and some envisioned the performance measures as potential tools in the process. “You’re going to check to see, every time you go in there if you see any of those things. It gives you some leverage.” Still others indicated that the measures were related to issues of personal concern such as bed sores, mental health, and daily activities. However, most participants did not feel they were necessarily of great salience, mentioning that they probably would “put [the measures] in long-term memory” or “keep it in the back of the mind.”

It is important to note that while caregiver definitions of quality diverged from more clinically-based quality measures, these views on quality were supported and validated by professionals and experts in focus groups and key informant interviews. In fact, there was broad consensus among caregivers, discharge planners, physicians, and industry experts that clinical performance measures should only be one part of the larger picture of nursing home quality, one which included the caregiver criteria related to cleanliness, caring, staffing, and customer service. One expert affiliated with the nursing home industry emphasized that “with nursing home quality the main thing is that it’s presented in a multi-dimensional way,” while a hospital discharge planner remarked that the proposed measures would be “helpful only if they’re part of something bigger.” Another expert with substantial professional experience in the nursing home industry emphasized the importance of quality of life measures. “A lot of the existing data doesn’t get at that. It’s too highly focused on the clinical aspects.”

#### *Caregiver Process of Selecting a Nursing Home*

Focus group findings and the literature (Rodgers, 1997) suggest that most caregivers have between three and twelve months to anticipate placing a loved one in a nursing home, but usually

postpone taking action until the last minute. Caregiver participants gave several reasons for delaying the selection of a nursing home, including the view of nursing homes as “the last resort” to be tried only after all other options were exhausted, and intense feelings of denial and guilt discussed in sections above. One participant noted the tendency when choosing a facility to “just wait, see, and pray.”

Complicating the decision-making process is the consideration of a number of different perspectives including those of the patient/resident, the family caregiver, the physician and other health care providers. The various players have different needs, values, and preferences that must be addressed (Miller, 1997; McCullough et al., 1993). The patient-resident may place priority on independence and social integration, the family may be more interested in ensuring their loved one’s physical safety, the provider or discharge planner may focus more on the patient’s medical needs, while the prospective nursing home may be thinking in terms of insurance coverage and financial resources. As a result, satisfying the disparate needs can be challenging.

Listed below are common steps in the process of selecting a nursing home as described in caregiver focus groups and expert interviews.

Trigger events: Decline of physical and/or mental health often served as the catalyst for caregivers to begin giving concerted thought to the possibility of nursing home placement, especially if the decline was posing a serious threat to the health and safety of the loved one. Trigger events could include hospitalization and subsequent discharge, discharge from home care, accidents or near accidents in the home, and the progression of longer-term illnesses. In general, the trigger event was characterized by a situation in which the strain on a caregiver to provide informal care to a dependent loved one was no longer tenable. According to one caregiver, “[you] always get to the breaking point and then do it. Your loved one begins doing unsafe things and it becomes too much to cope with.”

Researching options: A research phase generally followed the trigger event, and it was during this period in which most caregivers began looking into options and considering nursing home quality. Since most nursing home admissions occurred directly from the hospital, it was frequently the case that the discharge planner generated a list of prospective nursing homes which they encouraged caregivers to research. In placements occurring outside hospitals, caregivers were sometimes given referrals by the patient’s physician or sometimes took independent initiative and investigated options by obtaining leads from friends, acquaintances, or the Yellow Pages.

As discussed in the section regarding caregiver perceptions of quality, the indicators caregivers looked for in their research tended to be non-clinical and non-statistical in nature. Techniques consisted primarily on word-of-mouth recommendations and visits to prospective nursing homes when researching facilities.

Word-of-mouth recommendations originated from family, friends, coworkers, and other acquaintances who had previous personal or professional experience with nursing homes. One caregiver formerly in the profession of auto sales made a comparison emphasizing the

importance of customer satisfaction. “In the auto business we’re rated, but what really matters is what the customers say. For instance I would want to know, if your mother was in a nursing home, what would you say about it? It would be coming from trusting source.”

On-site visits were widely regarded by both caregivers and experts as an irreplaceable way of assessing the quality of a nursing home. Most caregivers in the focus groups reported making visits to at least one nursing home while in the decision-making process (with even a few reporting the use of specialized checklists), and hospital discharge planners reported strongly encouraging patient families to visit potential facilities. Furthermore, many other experts with substantial experience working with nursing home clinical performance measures or with facilities themselves maintained that while other forms of information can provide useful guidance in making a decision, “nothing replaces a visit to a facility.”

Caregivers conducting nursing home research often did so under tight time constraints and substantial amounts of stress, due to the gravity of the decision and frequently a loved one’s imminent discharge from the hospital. A consumer advocate commented on the subsequent need for information to be accessible and consumer friendly, stating that under such high-pressure circumstances, “most people are overwhelmed....They don’t want to pore through data and figure out what it means.”

Selecting a facility: A caregiver’s decision on a nursing home was dependent upon several other important factors as well, including proximity to the caregiver’s home, cost of care, insurance coverage, availability of beds, and availability of specialized services such as Alzheimer’s care. These factor often drastically reduced the number of facility choices for caregivers or left them with no choice at all. After weighing their findings on nursing home quality against these other important aspects, caregivers would make their selections.

### **Key Caregiver Influencers**

In order to fully understand the process by which caregivers make choices regarding nursing homes, it is necessary to identify their “key influencers” or “information intermediaries” whom they naturally encounter in the process of making a decision. These individuals or organizations may provide caregivers with nursing home quality information and may also aid them in interpreting and using the information. Since the research has pointed toward the common trend of caregivers waiting until the last minute before they make a nursing home decision, an important aspect of these key influencers is their availability to the consumer at the place and time they need and use quality information the most. Key influencers for this campaign include hospital discharge planners, physicians, consumer groups, community organizations, and the media.

A notable finding from the research was that similar to the caregiver audience, many of the discharge planners and physicians participating in the focus group research were also unaware of currently available information resources on nursing home quality. In the key informant interviews where more experts were familiar with the varying quality information resources, a commonly shared opinion was that available information could be presented in a more consumer-friendly way.

The sections below describe the role of each of these key influencers in informing and educating consumers about nursing home performance, and explores the advantages, disadvantages and concerns of each in this capacity.

### *Hospital Discharge Planners*

Hospitals are currently the source of the greatest number of nursing home admissions, due in large part to Medicare reimbursement policies. Given the tendency for most caregivers to delay research on and selection of a nursing home until the last minute, hospital discharge planners are often in a unique position to influence and guide consumer decisions.

As described in discharge planner focus groups, patient discharge planning typically begins on the day of admission into the hospital, and is completed within three to five days on average. After making an initial assessment of the patient's medical needs and social supports, a discharge planner generally approaches the patient's family and informs them of the need to admit their loved one into a nursing home. Planners then compile a list of potential nursing home options for the families, taking into consideration bed availability, payment restrictions, proximity to family members, medical needs, a short-term versus long-term stay, professional experience with a facility, and to varying degrees, nursing home quality. Discharge planners reported strongly advising families to visit facilities, particularly when they felt constrained by liability concerns, with some offering additional tips, checklists, or other materials to aid in the caregivers' research.

A strength of discharge planners as information intermediaries is that caregivers will almost certainly encounter them if admitting their loved ones to nursing homes from the hospital. Additionally, discharge planners are knowledgeable about local facilities and facility reputations, well-versed in the selection process, and are a logical information resource for consumers.

Quality information regarding specific nursing homes often reached discharge planners through former client feedback (especially those termed "returners," or nursing home residents who were re-hospitalized), and by word-of-mouth from colleagues. Discharge planners in the focus groups mentioned the potential benefit of obtaining quality information on nursing facilities as a way of keeping informed and current, especially in cases where they lack substantial experience with given nursing facilities, such as those in remote or rural areas. A final advantage of discharge planners as intermediaries is their view of themselves as patient advocates and as problem-solvers for patients and families, as well as for their hospital employers and healthcare colleagues. One discharge planner gave the following summary. "We are all patient advocates. We're there because we care, and to problem solve, and to be creative."

Limitations of hospital discharge planners as information intermediaries include heavy caseloads which can restrict the amount of available time to spend with patients and their families. Discharge planners described managing 15 to 50 cases at any given point. Time constraints have been noted as a major barrier to patient education and counseling in other studies on hospital discharge planners and geriatric care managers (Potthoff et al., 1997; Degenholtz et al., 1997). Additionally, the job of discharge planner can also include responsibility for hospital utilization review and minimizing lengths of patient stays. This can create incentives for discharge planners to usher cases through as quickly as possible, and create disincentives for providing potentially

negative information to consumers that may hinder the discharge process. This situation potentially generates perception problems, complicating the view of the discharge planner as a patient advocate and information intermediary. Patients, families, and some physicians may perceive discharge planners as adversaries or working to “kick patients out of the hospital.”

Finally, potential for conflict of interest and issues of liability may limit the effectiveness of discharge planners as intermediaries. Conflict of interest may occur if ties exist between hospitals and specific nursing homes, such as in-house or other affiliated facilities. Such relationships have the potential to bias advice or recommendations that a discharge planner gives. Liability was a major concern voiced by discharge planners who often were discouraged from making either explicit or implicit recommendations, due to fear of blame by patients and families for a non-ideal placement, as well as fear of resistance or pressure from nursing homes responding to poor recommendations.

#### *Physicians/Nurses*

Primary health care providers, especially physicians and nurses, were also frequently mentioned by caregivers as potential advisers on nursing home and nursing home quality information. As one expert articulated, “providers, by virtue of their perceived expertise, can hold the balance of power during the care arrangement process, particularly following hospitalization” (Jenkins, 2000).

According to discussion from the physician focus group, while doctors may be willing to refer patients to nursing home quality information, they hold a number of reservations regarding an expanded advisory role. As with hospital discharge planners, physicians raised concerns over liability in making recommendations for certain nursing facilities over others, and encounter time and reimbursement constraints in counseling families or patients.

Furthermore, several physicians in the focus group expressed uneasiness over CMS’s proposed performance measures fearing that consumers may negatively misinterpret them and foster “unrealistic expectations” of nursing homes, when the measures could in fact represent natural events in the dying process. Others questioned the reliability and validity of some of the clinical quality information with one physician stating that “the measures are very case-mix dependent and it may be damning to some good facilities.... Is this clear and fair? Unless you know the background or the case-mix, you may be misled by results.” A few others added that if personally choosing a nursing home for a loved one, they would rely on other less clinically oriented measures of quality such as cleanliness and staffing.

Physicians in the focus group tended to sympathize with the nursing home industry and felt that it suffers an unduly poor reputation. One participant emphasized the need to engage the nursing home industry in CMS’s public reporting initiative, mentioning the need to work with facilities on quality improvement. “Medicare has to take responsibility. There has to be accountability. They can't just point fingers. They have to be willing to take action. Q.A. [quality assurance] should also be Q.I. [quality improvement]. This campaign will make the nursing home industry feel more beleaguered, and will make consumers upset.”

### *Consumer Groups and Community Organizations*

Consumer advocacy groups, community organizations and local agencies form another group of key caregiver influencers. Such organizations include area agencies on aging, senior services organizations, adult day care, home health agencies, meals on wheels programs, senior centers, AARP, state departments of health, and ombudsmen.

Their strengths as information intermediaries include their familiarity with local resources and experience in providing consumers with information, education, and counseling about issues related to aging and long-term care. Additionally, key informant interviews with representatives of such groups indicated that many are highly motivated and are able to give individualized assistance without the time constraints and liability concerns that discharge planners and physicians encounter.

Caregiver organizations such as local chapters of the Alzheimer's Association and hospital-based support groups for caregivers can be well-positioned to provide advice and support about selecting a nursing home to some members of the target audience. Resident councils in 91% of nursing homes and family groups in 45% of nursing homes provide strong presence (Harrington et al., 2000) and good potential as an information resource. Expert interviews have also suggested churches key influencers, particularly for African-American communities and populations in the South.

Limitations of community organizations include smaller staff numbers and budgets, with many relying heavily on volunteer labor. Such groups may not be prepared to communicate complex issues on nursing home quality outside of their specific charge and may lack the capacity for attaining a broad audience reach.

Regarding the proposed measures, these intermediaries again raised the issue that clinical performance measures alone provide too narrow a focus on quality and require a broader context. As one ombudsman commented, "if [the proposed measures] are the only quality information given, this is very limited. You need to educate consumers on the overall process and be broad-based. Tell them what good quality is and how to look for it." Finally, some of these influencers also expressed concern over the credibility of the campaign objectives with a few questioning whether the launch of an information campaign would act as a substitute for enforcing nursing home regulations.

### *Media*

Throughout the research, caregivers, providers, and key informants have all suggested that the media has played a significant role in shaping the image of nursing homes and nursing home quality for the public and policymakers. The strength of the media as an information intermediary is its broad reach across all potential audiences. This strength gives the media potential to increase public awareness of the need for nursing home quality information and of underutilized quality information resources.

Potential limitations of the media include its negative focus with regard to nursing homes. This was suggested by the fact that many respondents, both caregivers and experts, consistently referred to horror stories they heard or read about in the news which concentrated on severe

instances of abuse and neglect in specified nursing facilities. Caregivers noted how such coverage heightened their fears of nursing homes, and providers lamented that the media never carried positive news about nursing homes noting that such horror stories created a contentious relationship between consumers, providers, and the nursing home industry. The media is also limited in its ability to target and reach caregivers at the time at which they are actually seeking quality information and selecting a nursing home.

Reporters have mentioned using ombudsmen, state agencies, CMS and [www.medicare.gov](http://www.medicare.gov) as sources when collecting research on nursing homes. However, it remains unclear how well the media understands issues related to nursing home quality, and while they could play a positive role in the Consumer Choice Campaign, would likely require further education on the topic.

## DISCUSSION

In seeking to address the question of how to motivate consumers to use nursing home quality information to make better informed decisions, opportunities and barriers for the Consumer Choice Campaign appeared as researchers developed a better understanding of the target audience and its decision-making environment. The sections that follow describe opportunities and barriers and provide initial direction for the development of campaign strategy.

### Opportunities

#### *Demand for Information*

Focus group and key informant research indicated that caregiver demand exists for nursing home quality information, particularly at the time that caregivers are making placement decisions. While often brief, it is in that stage that consumers are “hungry” for nursing home quality information and are actively seeking it to help them determine which of their facility options will offer the best care and environment for their loved ones. In addition, some caregivers also mentioned that they could envision using CMS’s proposed measures to monitor the care of their loved ones, especially if the measures were incorporated into something they could concretely use, such as a checklist.

#### *Understanding Caregiver Motivations*

The research findings revealed a clear picture of caregiver motivations with regard to nursing home quality and selection. Caregivers are motivated to seek quality information by their desire to make the best nursing home choice for their loved ones. However, they often must first overcome the guilt, family conflict, and overwhelming nature of the decision-making process. Caregivers also emphasized that a strong potential benefit of quality information would be if it helped reduce their sense of guilt.

#### *Easily Identifiable and Easily Located Target Audience*

Knowledge of the nursing home decision-making process and of the high incidence of nursing home placements originating from hospital discharge points toward a strong opportunity for dissemination of quality information involving hospital discharge planners. A large proportion of caregivers choosing nursing homes for their loved ones will encounter hospital discharge planners during their decision-making process. However, it must be acknowledged that caregivers who do not admit a loved one to a nursing home immediately after hospitalization will be more difficult to identify and reach.

#### *Willing Intermediaries*

Discharge planners mentioned that more nursing home quality information and better information would help them in their ability to help caregivers effectively choose nursing homes. Their view of themselves as patient advocates and as an appropriate resource for caregivers seeking nursing home quality information provides an important opening for the campaign. Another opportunity is presented in the willingness of physicians to refer patients and their

families to sources of quality information or to community organizations that can provide personal assistance in the selection process.

## **Barriers and Challenges**

### *Guilt and Stigma*

The guilt and stigma associated with placing a loved one in a nursing home inhibits family caregivers from seeking out information on nursing homes and planning in advance. Although most caregivers can anticipate the potential need for nursing home care for number of months leading up to the placement, few make advance plans due to denial, guilt, and family conflict. Caregivers see nursing homes as a care option of last resort, and often face resistance from both their loved ones and other family members who see admission as abandonment.

### *Disconnect Between Caregiver Perceptions of Quality and Proposed Measures*

Caregivers and community organizations associate nursing home quality more with concepts such as cleanliness, caring, and staffing than with the more clinical aspects of quality in CMS's proposed performance measures. While not necessarily opposed to using clinical measures, these measures do not naturally resonate with caregivers and would require fuller context, explanation, and linkage to consumer definitions of quality in order to be considered.

### *Limited Choice of Nursing Homes*

Many caregivers have few actual options in nursing homes due to a variety of factors from residing in a rural area where there are fewer facilities, to specialized medical requirements of their loved ones, to a scarcity of available beds at the time of admission. Furthermore, individuals who have exhausted their savings and their Medicare eligibility may have a particular difficulty locating nursing homes willing to accept them. Thus for a portion of the target audience, the concept of using quality information in the context of nursing home choice may not be relevant.

### *Negative Associations with Proposed Measures*

Caregiver tendencies to negatively perceive CMS's proposed nursing home performance measures as symptoms of abuse and neglect rather than as measures of quality may exacerbate the stress and guilt that caregivers experience during the nursing home selection process. Additionally, such negative associations may further reinforce a caregiver's worst fears about nursing homes.

### *“Problem-focus” of performance measures may create an adversarial relationship with providers and nursing home industry*

The nursing home industry is apprehensive that presentation of the quality data will focus consumers only on the negative aspects of nursing home quality such as bed sores and restraint use, and will not recognize or reward truly well-performing facilities. There is also concern among physicians, discharge planners, and the industry that the campaign will ignore a necessary quality improvement component, exposing problems in nursing homes without helping to solve them. As one physician put it, there is fear that the effort will be more “naming, blaming and

shaming of an already beleaguered industry.” Additionally, nursing homes and consumers alike expressed concern that quality information alone will not improve nursing home quality.

#### *Litigious eldercare environment*

Given the negative connotation and problem-focus of proposed measures, many providers feared that a consumer campaign focusing on the proposed measures would lead to increased litigation against nursing homes. This seemed a particularly sensitive issue in Florida and may have similar effects in other areas of the country as well.

#### *Concerns about reliability of MDS data*

A number of stakeholders expressed concern over various aspects of the data including:

- ◆ Propensity for data entry errors and coding issues in the MDS data
- ◆ Timeliness of the data, with the potential for some data to be over 60 days old
- ◆ Lack of federal standards for nursing home quality with regulations implemented differently in different states
- ◆ Risk-adjustment and readiness of the data for public reporting

#### *Campaign efforts may overlap with state and private efforts to provide nursing home information*

Currently, many states already collect and publicly report their own nursing home quality information. The multiplicity and fragmentation of nursing home information and assistance programs at the federal, state, and local level may be confusing to consumers (Reinhard and Scala, 2001). Furthermore, states such as Oregon, Washington, and Florida have implemented programs to reduce admissions to nursing homes, which may complicate CMS efforts to generate consumer demand for nursing home quality information. Additionally, there are also private efforts to provide nursing home quality information. Many consumer reports, local newspapers, local advocacy organizations, and private care managers offer consumers information and assistance in identifying high quality nursing facilities. The challenge to CMS will be finding a way to differentiate and integrate the proposed measures with the existing information and initiatives.

### **Preliminary Conclusions**

The objectives for this research were to identify the campaign’s target audience, map the audience’s decision-making environment to ultimately understand their motivations for using nursing home quality information. Findings point to three central conclusions that provide a foundation for the development of campaign strategies.

*Caregivers are the primary audience for CMS’s Consumer Choice Campaign and may be motivated to use nursing home quality information.*

Findings from this study offer key points that can be used in marketing quality information to caregiver audiences. In developing its campaign strategy for motivating caregivers, CMS should consider the following:

- ◆ Caregivers do not see the linkages between CMS's objective quality of care measures and their own subjective quality of life ones and tend to call into question the validity or usefulness of the CMS measures because of this disconnect. Therefore, effective messages must educate caregivers on the connection between quality of care and quality of life.
- ◆ Effective messages must be presented within the full context of nursing home quality that includes both quality of life and quality of clinical care.
- ◆ CMS's nursing home quality information has potential appeal for caregivers if it helps to ameliorate the problems associated with nursing home decision-making including: guilt, stigma, fear of the unknown, lack of control and family pressure and conflict.
- ◆ Caregivers' central concern is securing and maintaining a safe, caring, and comfortable nursing home placement for their loved ones. In successfully marketing quality information to them, CMS must show that use of this information can lead to the outcomes caregivers desire.

*Discharge planners are key influencers in addition to doctors/nurses, consumer groups, and community-based organizations.*

The majority of nursing home placements are made in the hospital setting. Mapping of the decision-making process suggests that caregivers desire and may use nursing home quality information primarily at the time they are making nursing home decisions and rely on hospital discharge planners to help them access needed information. With this in mind, CMS can:

- ◆ Educate discharge planners on quality and provide requested CEU coursework as a way of getting them engaged.
- ◆ Provide discharge planners with a one or two-page patient/family handout discussing nursing home quality. Discharge planners would prefer the handout in a downloadable format that can be quickly personalized and reproduced.
- ◆ Utilize other channels in supporting a main discharge planner strategy. The channels include physicians who may intervene prior to a crisis point by educating caregivers about nursing home placement and quality; organizations such as the Alzheimer's Association who have vested interest and strong experience in counseling caregivers; and media to inform the professional and general public of the existence of CMS's new quality measures.

*Stakeholders are looking for CMS to work collaboratively to position quality as positive rather than punitive*

Literature suggests (Kaplan and Norton, 1996 and Harry and Schroeder, 2000) that quality initiatives work best in collaborative, supportive environments. Our research indicates that while CMS has taken successful steps to engage the industry in the effort to select MDS performance measures, potential continues to exist for nursing homes to perceive the CMS reporting initiative as another punitive measure against their already beleaguered industry. This possibility of industry resistance, together with negative media coverage of nursing homes and pejorative preconceptions caregivers have of nursing homes in general, has the potential to undermine any positive impact of CMS's public reporting effort. CMS can address stakeholder concerns by:

- ◆ Better communicating with stakeholders about the quality initiative and inviting their input into the strategy development for a national campaign.
- ◆ Publicly positioning the quality initiative as a proactive process of helping the industry ensure the best possible care for nursing home residents. Continuing to support behind the scenes efforts to develop and maintain the quality measurement and improvement infrastructure.

**APPENDIX I - REFERENCES**

- Angel JL, Angel RJ, McClellan JL, Markides KS, 1996. Nativity, Declining Health, and Preferences in Living Arrangements Among Elderly Mexican Americans: Implications for Long-Term-Care. *The Gerontologist* 36(4): 464-73
- Coleman, B, 1997. New Directions for State Long-Term Care Systems: Volume IV: Limiting State Medicaid Spending on Nursing Home Care.” AARP, Public Policy Institute Publication
- Collopy BJ, 1998. Autonomy in Long Term Care: Some Crucial Distinctions. *Gerontologist* 28(3):10-17
- Collopy BJ, 1990. Ethical Dimensions of Autonomy in Long-Term Care. *Generations* 14 (Supplement ):9-12
- Degenholtz H, Kane RA, Kivnick HQ, 1997. Care-Related Preferences and Values of Elderly Community-Based LTC Consumers: Can Case Managers Learn What is Important to Clients? *The Gerontologist* 37(6): 767-776
- Gabrel CS, 2000. An Overview of Nursing Home Facilities: Data from the 1997 National Nursing Home Survey.” Advance Data from the Vital and Health Statistics; no. 311
- Gold MF, 1993. Ethical Decision Making. Creating a Framework for Long Term Care. *Provider* 19(5):28-9, 31-2.
- Harry, M, Schroeder, R, 2000. *Six Sigma: The Breakthrough Management Strategy Revolutionizing the World’s Top Corporations*. New York: Doubleday, 2000.
- Jenkins CL, 2000. Care arrangement decisions for frail older women: quantitative and qualitative perspectives. *Journal of Women & Aging* 12(4):3-20.
- Kaplan, R, Norton, D, 1996. *The Balanced Scorecard: Translating Strategy into Action*. Boston: Harvard Business School Press, 1996.
- McCullough LB, Wilson NL, Teasdale TA, Kolpakchi AL, Skelly JR, 1993. Mapping Personal, Familial, and Professional Values in Long-Term Care Decisions. *The Gerontologist* 33(3): 324-332.
- Miller NA, 1997. Patient Centered Long-Term Care. *Health Care Financing Review* 19(2):1-10.
- National Family Caregivers Association, 2000. *Random Sample Survey of 1,000 Adults Sponsored by Aleve*. from <http://www.nfcacares.org/>.

- National Family Caregivers Association and Fortis Long Term Care, 1998. *Caregiving Across the Life Cycle* from <http://www.nfcacares.org/>.
- Potthoff SL, Kane RL, Franco SJ, 1997. Improving Hospital Discharge Planning for Elderly Patients. *Health Care Financing Review* 19 (2): 47-72
- Reinhard SC, Scala MA, 2001. Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States. *AARP Public Policy Institute Issue Paper*, #2001-12
- Rodgers BL, 1997. Family Members' Experiences with the Nursing Home Placement of an Older Adult. *Applied Nursing Research* 10(2):57-63
- Sahyoun NR, Pratt LA, Lentzer H, Dey A, Robinson KN, 2001. The Changing Profile of Nursing Home Residents: 1985-1997. *Ageing Trends*: No. 4. Hyattsville, MD: National Center for Health Statistics.
- Tymchuk AJ, Ouslander JG, Rahbar B, Fitten J, 1998. Medical Decision-Making Among Elderly People in Long Term Care. *Gerontologist* 28(3):59-63.
- United States General Accounting Office, 1999. Nursing Homes: Additional Steps Needed to Strengthen Enforcement of Federal Quality Standards. GAO/HEHS 99-46
- United States General Accounting Office, 2002. More Can Be Done to Protect Residents from Abuse. GAO 02-312

## **APPENDIX II – PROPOSED PERFORMANCE MEASURES**

At the time of this research, CMS had proposed the following nursing home performance measures from the Minimum Data Set (MDS) for public reporting.

- ◆ Physical restraints
- ◆ Pressure sores
- ◆ Weight loss
- ◆ Infections
- ◆ Pain management
- ◆ Decline in activities of daily living
- ◆ Use of anti-psychotic drugs without a psychiatric diagnosis
- ◆ Managing delirium
- ◆ Improvement in walking

### APPENDIX III - List of Key Informants

Name of Key Informant	Type
American Association of Homes and Services for the Aging	Association of Long Term Care Facilities
American Health Care Association	Association of Long Term Care Facilities
North Mississippi Medical Center	Community Hospital
Kalispell Regional Medical Center	Community Hospital
National Indian Council on Aging (NICOA)	Consumer advocacy (American Indian/Alaskan Natives)
National Citizens' Coalition for Nursing Home Reform	Consumer advocacy group
South Dakota Chapter of Alzheimer Association	Consumer advocacy group
Friends & Relatives of the Institutionalized Aged (NY)	Consumer advocacy group
Center for Medicare Advocacy	Consumer advocacy group
Massachusetts Chapter of the Grey Panthers	Consumer advocacy group
Families for Improved Care (OH)	Consumer advocacy group
National Asian Pacific Center on Aging	Consumer advocacy group (Asian/Pacific Islander)
Director of Family Council	Nursing home family council
<a href="http://www.careguide.com">www.careguide.com</a>	Eldercare case management company
Center for Eldercare Choice	Employee Assistance Program (Elder Care Consultation and Referral Program)

Name of Key Informant	Type
University of Washington Medical Center	Hospital Discharge Planner
Cleveland Clinic (OH)	Hospital Discharge Planner
The Mount Sinai Hospital, Department of Social Work Services	Hospital Discharge Planner
The Tampa Tribune	Media
Consumer Reports	Media
Massachusetts Nursing Home (9 health deficiencies on last inspection)	Nursing home
Long Term Care Ombudsmen Program (OH)	Ombudsman
Florida State Long-Term Care Ombudsman	Ombudsmen
National Long Term Care Ombudsman Resource Center	Ombudsmen
Physician	Primary Care Provider, Researcher
Arkansas Foundation for Medical Care, Inc.	PRO
MassPRO	PRO
CMRI	PRO
Carelink (RI)	Provider Organization
Illinois Geriatrics Society	Provider Organization
The John A. Hartford Foundation Institute for Geriatric Nursing	Provider Organization
Center for Medicare Education	Research for Medicare Beneficiaries

Name of Key Informant	Type
Academic, Brown University	Researcher
Academic, University of Texas	Researcher (Mexican Americans and Long Term Care)
Academic, Brown University	Researcher, Nursing home board member
Evergreen Senior Housing (VT)	Senior Housing
California Health Care Foundation	Research, policy, and communications
Kaiser Family Foundation	Research, policy, and communications

**APPENDIX IV- Interview Guide for Key Informant Interviews - Stakeholders who provide direct services to consumers and caregivers**

**Introduction**

My name is \_\_\_\_\_ and I work for Barents Group of KPMG Consulting. We are working with the Centers for Medicare and Medicaid Services and are interested in getting your opinions and advice on how to educate consumers about Nursing Home Quality. I have some questions I'd like to ask you that would take about one hour to answer. Would you be willing to help us out with an interview?

*[If no, thank and terminate call]*

*[If yes]* Is now a convenient time to talk?

*[If no]* Could you suggest another time that would be more convenient?

*[If yes, continue]*

My associate, \_\_\_\_\_, is also on the call to take notes. I would like to tape record this interview, so that we can accurately capture your remarks in our report. I may quote you in the report, but your name will not be revealed to anyone except those on the research team. Do I have your consent to tape-record the interview?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

Again, the purpose of these interviews is to learn more about communicating nursing home quality to consumers. Specifically, we're interested in how various audiences perceive the utility of public reporting of Nursing Home Quality information and to learn what would make the information more relevant and useful to direct users (such as consumers and their family members) and indirect users (such as advocacy organizations, hospital discharge planners, and media). Do you have any questions before we begin the interview?

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**NOTE: Because key informants perform different roles, the questions below will be customized to the respondent.**

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### **Organization Background Information**

1. Please give your name and title and describe your roles and responsibilities in your organization? [Probe to determine whether respondent counsels seniors, develop materials, etc.]
2. Please describe your organization's role in helping seniors and their families choose nursing homes. Does your organization serve all seniors and family members or a particular subpopulation (e.g., minority groups, low-income populations)?

### **Characteristics of Consumers of Nursing Home Information**

3. Who contacts you/your organization for nursing home information?
4. At what stage or point in time do people usually come to you with questions? In other words, how much time in advance of nursing home admission do people inquire about quality of nursing homes?
5. What are the most common questions you receive about choosing nursing homes?
6. What information do you provide them about nursing homes? How does your audience use the information you make available?
7. What would you say is the current level of awareness of nursing home quality among your constituency?
  - ◆ What are common beliefs about nursing homes/nursing home quality?
  - ◆ What are common misconceptions about nursing homes/nursing home quality?
  - ◆ What do you believe drives or influences the way people think about nursing home choice and nursing home quality?
8. What is the level of interest in nursing home quality among your clients?
9. What types of information about nursing home quality do you think would be most helpful to your audience or constituency? Why?

### **Sources of Nursing Home Quality Information**

10. Does your organization currently provide information about nursing home quality?
  - ◆ If no, what prevents you from disseminating or using this type of information? Any barriers?
  - ◆ If yes, please describe the purpose of the information, the information format (print materials, web site, etc.), the strengths and limitations of the information.

- ◆ Have you encountered any problems when disseminating or using this information? (Probe regarding comprehension problems, political concerns)
  - ◆ How do you get consumers interested in nursing home quality?
11. Are there any other sources of information about nursing home quality in your area? Do you refer consumers to other organizations?
12. What type of information or services do they provide?
- ◆ Are there any services that are particularly successful or effective? Who do you think can most effectively communicate with consumers about nursing home information?

### **Communication Practices**

13. How do you reach seniors and their families (brochures, health fairs, hotline, web page)?
14. What have you learned about counseling consumers about selecting nursing homes?
- ◆ What communication techniques work the best with your audience? (interactive, group, one-on-one, etc.)
  - ◆ In your experience, what information formats are best for seniors? For their caregivers?
  - ◆ What messages resonate?
15. What are some of the major challenges and barriers to communicating and educating your audience/constituency ?
- ◆ Do you face any legal constraints?
  - ◆ Do you face any resources constraints? (lack of adequate staffing, funding, materials)
  - ◆ Do consumers face or perceive any constraints when thinking about nursing home quality and choosing nursing homes?

### **Campaign**

16. If Medicare were to conduct an intense communication campaign about Nursing Home Quality, how would your organization respond to such information? What role would you see your organization playing?
- ◆ [Probe to determine whether would use/not use campaign materials, would make available on request, actively disseminate, etc.]
  - ◆ How do you think your audience/constituency would respond?

17. What, in your opinion, should Medicare's role be in communicating with consumers about nursing home quality? What should Medicare's role be in supporting partners' efforts to communicate nursing home quality information?

**Closing**

18. Is there anyone else you think we should talk to because they would have good advice about how to disseminate information about nursing home quality?
19. Do you any additional comments and recommendations related to our discussion today?

*Thank you very much for your time and for your participation.*

## APPENDIX V- Interview Guide for Stakeholders who do not provide consumer services

### Introduction

My name is \_\_\_\_\_ and I work for Barents Group of KPMG Consulting. We are working with the Centers for Medicare and Medicaid Services and are interested in getting your opinions and advice on how to educate consumers about Nursing Home Quality. I have some questions I'd like to ask you that would take about 30 minutes to one hour to answer. Would you be willing to help us out with an interview?

*[If no, thank and terminate call]*

*[If yes]* Is now a convenient time to talk?

*[If no]* Could you suggest another time that would be more convenient?

*[If yes, continue]*

My associate, \_\_\_\_\_, is also on the call to take notes. I would like to tape record this interview, so that we can accurately capture your remarks in our report. I may quote you in the report, but your name will not be revealed to anyone except those on the research team. Do I have your consent to tape-record the interview?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

Again, the purpose of these interviews is to learn about the best way to give consumers information about nursing home quality. Specifically, we're interested in how various audiences perceive the utility of public reporting of Nursing Home Quality information and to learn what would make the information more relevant and useful to direct users (such as consumers and their family members) and indirect users (such as advocacy organizations, hospital discharge planners, and media). Do you have any questions before we begin the interview?

---

**NOTE: Because key informants perform different roles, the questions below will be customized to the respondent.**

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### **Organization Background Information**

1. Please give your name and title and describe your role(s) and responsibilities in your organization.
2. Please describe your organization's mission and primary activities. (Probe to determine how it relates to helping seniors and their families choose nursing homes.)
3. Who is your organization's primary client/audience/constituency?

### **Existing Awareness and Attitudes about Nursing Home Quality**

4. How would you describe the quality of nursing homes in the U.S.?
  - ◆ How would you describe the quality of nursing homes in your city or state?
5. In your opinion, does nursing home quality vary or are most nursing homes the same? What makes you think that?
6. What are the characteristics of a high quality nursing home?

### **Demand for Information about Nursing Home Quality**

7. What is the level of interest in nursing home quality among your clients/audience/constituency?
  - ◆ What is your audience most interested in or concerned about?
  - ◆ If interest is low, what would motivate your audience to seek out such information?
8. How do you think information about nursing home quality would benefit people in your audience?
  - ◆ Who is most likely to benefit from this information?
  - ◆ When is this information most likely to be used?
  - ◆ For what purposes is it most likely to be used?
9. What factors do you think would prevent people in your audience from seeking out and/or using information about nursing home quality? (Probe regarding denial, comprehension problems, lack of time, etc.)
  - ◆ What is the best way to overcome such barriers?
  - ◆ What has worked in the past?
  - ◆ What types of information about nursing home quality do you think would be most helpful to your audience or constituency? Why?

- ◆ What is the best way to reach your audience with information about nursing home quality?
10. What techniques have been effective in the past? What formats are most popular? What messages have been most effective?

### **Current Information Resources**

11. Please name the sources of information about nursing home quality in your area.
- ◆ What type of information or services do they provide?
  - ◆ Are there any services that are particularly successful or effective?
  - ◆ What factors contribute to its effectiveness?
12. What problems and limitations have you encountered with this information?
13. What types of information about nursing home quality have you produced in the last year? Please describe the content and the format.
14. How has your audience responded to that information?
- ◆ Do some respond differently than others? If so, how?
  - ◆ In your opinion, what is the reason for the different responses?
15. In your opinion what is the most reliable and accurate source of information of information about nursing home quality?
- ◆ What makes it reliable and accurate?
  - ◆ What is the most useful source of information about nursing home quality?
  - ◆ What makes it useful?

### **Suggestions Regarding the Consumer Choice Campaign**

16. If Medicare were to conduct an intense communication campaign about Nursing Home Quality, which organizations do you think would be most qualified to be involved in such a campaign? (Probe regarding advocacy organizations, nursing associations, discharge planners, etc.)
- ◆ What role would these organizations play?
  - ◆ What support would these organizations need in order to be involved in such a campaign?
  - ◆ What factors would prevent them from distributing information about nursing home quality?
  - ◆ What types of organizations should not be involved in such a campaign? Why? (Probe to see whether some partners are perceived as biased.)

17. If Medicare were to conduct an intense communication campaign about Nursing Home Quality, how would your organization respond?
- ◆ What role would you see your organization playing?
  - ◆ How could Medicare support your efforts? (training, materials, funding)
  - ◆ If funding were limited, what would be the most effective way to support your efforts?
  - ◆ How do you think your audience/constituency would respond?
18. What, in your opinion, should Medicare's role be in communicating with consumers about nursing home quality? What should Medicare's role be in supporting partners' efforts to communicate nursing home quality information?

### **Closing**

19. Is there anyone else you think we should talk to because they would have good advice about how to disseminate information about nursing home quality?
20. Do you any additional comments and recommendations related to our discussion today?

*Thank you very much for your time and for your participation.*

**APPENDIX VI- Characteristics of Focus Group Participants****Focus Group Participants**

Audience	Number of Participants
Caregivers	52
Hospital Discharge Planners	19
Physicians	10

## APPENDIX VII- Focus Group Discussion Guide for Caregivers

### WELCOME

Thank you for joining us today, my name is \_\_\_\_\_. I am working on a project for the federal government. The purpose of this project is to give consumers information about nursing homes. We have invited you to this discussion because all of you help an older relative with their healthcare decisions.

Before we start today, I'd like to talk about a few things:

- ◆ I am interested in all of your ideas, comments, and suggestions. There are no right or wrong answers to the questions
- ◆ I'd like to hear from everyone
- ◆ All comments—both positive and negative—are welcome. Please don't worry about offending me with anything you might say—it's important that I know how you feel.
- ◆ Please feel free to agree or disagree with one another. We would like to have many points of view.
- ◆ Behind me is a one-way mirror. Behind it are people helping me today.
- ◆ This discussion is being video- and audio-taped, so that we can take better notes on what you all have to say. We may also show the tapes to others who are interested in the results but could not be here today. Before coming into the room you signed a release giving us permission to video/audio tape you during this discussion. All comments are confidential and used for research purposes only.
- ◆ I'd like this to be a group discussion, so you needn't wait for me to call on you. But please speak one at a time, so that the tape recorder can pick up everything.
- ◆ Your insights today will help guide the development of health communications materials—that is, messages about nursing homes that you might see on websites or in brochures, flyers or articles—that the federal government is doing for people like you.
- ◆ Does anyone have any questions before we begin?

### DEFINITION OF NURSING HOME QUALITY

- ◆ On pad of paper, write the numbers 1, 2, and 3. Now write next to the numbers the first three things that pop to mind when I say "Nursing Home Quality"
- ◆ What did you write down? What is nursing home quality?

### PROCESS

We're going to be discussing about nursing home quality tonight and one of the reasons we're interested in talking with you is because the people you help care for are still in pretty good

health and probably are not likely to need a nursing home soon, and so you may not have done a lot of thinking about it yet. We'd like to kind of map out how you imagine you might go through the process of choosing a nursing home for a relative or friend if they were to need it one day. I'm going to try to sketch the map we come up with on this pad.

- ◆ First think about when you would start (or started) looking for a nursing home. How would you know it's time to start thinking about it? When do you think is the *best* time to start thinking about it? (Probe re: procrastination)
- ◆ What relative do you have in mind? Are there any of you caring for people who don't speak English?
- ◆ What's the first thing you would do?
- ◆ Who is the first person you would turn to? Why?
- ◆ What might you ask that person about? Who else might you look to for help? Why? (Probe regarding physicians, hospital staff, friends, consumer organizations, etc.)
- ◆ What would be your biggest concerns or worries?
- ◆ What questions would you have?
- ◆ How would you make your decision about which nursing home to go with? (Probe re: proximity, insurance, etc.) What about quality?
- ◆ How would you go about educating yourself about nursing home quality? Who are the "authorities" in your life on nursing home quality or making a good nursing home decision? How do you know who or what to trust?
- ◆ How might Medicare be able to help you? What could it do? Does Medicare have a place in this process? Do you think that they currently have any of this information?
- ◆ What if I told you that Medicare, or the government has information on nursing home quality for choice-making, what would be the problem that is solved, out of all the ones we discussed? What would be the benefits? Would you look at Medicare?
- ◆ What would be the best way to get this information to you? If you got this information now, would you pay attention to it?

## QUALITY MEASURES

Now I'm going to pass out a sheet of paper to each of you with some examples of nursing home quality. Please take a minute or so to look at them. If there anything which you find confusing or have questions about, please put a question mark on the sheet and go to the next word on the list.

The sheets will display the following measures

- ◆ physical restraints
- ◆ pressure sores

- ◆ weight loss
- ◆ infections
- ◆ pain management
- ◆ decline in activities of daily living
- ◆ use of anti-psychotic drugs without a psychiatric diagnosis
- ◆ managing delirium
- ◆ improvement in walking
  
- ◆ What are your thoughts about these measures?
- ◆ How do these measures line up with the list I asked you to make in the beginning?
- ◆ If the government was to provide you with the type of information presented on these cards, what would you do with it? How likely would you be to use it?
- ◆ When would this type of information be most helpful?
- ◆ What's the right way to present this information to you?
- ◆ How would this information affect which nursing home you chose for your parent?
- ◆ Would this information help you choose a good nursing home for your relative? If so, how? How would you feel about using these measures to pick a nursing home for a loved one?
- ◆ If you were feeling a lot of stress at the time, would you look at this?
- ◆ Would Medicare be a good source?
- ◆ Would you take the Medicare guide to nursing homes if you planned to visit them?

### **WRAP –UP**

We are almost done with our discussion today. Does anyone have any other comments or suggestions about what is the best way to give people information about the quality of nursing homes?

**Thanks again for your help today.**

## APPENDIX VIII- Focus Group Discussion Guide for Physicians

### I. Introduction

Thank you for joining us today. My name is \_\_\_\_\_ and I am here to talk to you about nursing home quality. I am working on a project for the federal government. The purpose of this project is to give consumers information about the quality of nursing homes in their area. We have invited you to this discussion because all of you have had patients who have been admitted into a nursing home.

Before we start today, I'd like to talk about a few things:

- ◆ I am interested in all of your ideas, comments, and suggestions. There are no right or wrong answers to the questions
- ◆ I'd like to hear from everyone
- ◆ All comments—both positive and negative—are welcome. Please don't worry about offending me with anything you might say—it's important that I know how you feel.
- ◆ Please feel free to agree or disagree with one another. We would like to have many points of view.
- ◆ Behind me is a one-way mirror. Behind it are people helping me today.
- ◆ This discussion is being video- and audio-taped, so that we can take better notes. on what you all have to say. We may also show the tapes to others who are interested in the results but could not be here today. Before coming into the room you signed a release giving us permission to video/audio tape you during this discussion. All comments are confidential and used for research purposes only.
- ◆ I'd like this to be a group discussion, so you needn't wait for me to call on you. But please speak one at a time, so that the tape recorder can pick up everything.
- ◆ Your insights today will help guide the development of health communications materials—that is, messages about nursing homes that you might see on websites or in brochures, flyers or articles—that the federal government is doing for people like you.
- ◆ Does anyone have any questions before we begin?
- ◆ Please tell us your name and where you work.
- ◆ What is the best thing about being a doctor for elderly patients? What is the most difficult aspect of caring for elderly patients?

### II. Current role

- ◆ As your patients grow older and become more frail, how do you bring up the subject of nursing homes either with your patient or their family?

- ◆ When do you bring it up?
- ◆ What do you tell them?
- ◆ What actions do you encourage them to take?
- ◆ Many people find it difficult to talk about nursing homes with senior citizens. What types of problems have you had when discussing nursing homes with your patients?
- ◆ How do you deal with the difficulties?
- ◆ Many patients put off planning for long term care until the last minute. What would encourage you to advise families to start planning early on?
- ◆ Do your patients ever ask for recommendations of nursing home? If so, what do you tell them?
- ◆ Some doctors are uncomfortable about offering information or advice about choosing nursing homes. Others do not have a have a problem with this. What factors might would encourage or discourage physicians to offer patients information about nursing home quality?
- ◆ What would be your comfort level in offering advice, recommendations?"
- ◆ Probe to identify perceived restrictions such as conflict of interest, affiliations with NH, liability concerns
- ◆ What information do you currently provide to your patients about nursing homes and long term care?

*Probe to determine if they refer patients elsewhere.*

*If they provide advice, what type of advice*

- ◆ If the doctor does not provide information and advice on nursing home, ask whether there is someone else in the practice that does.

### **III. Response to Nursing Home Measures**

Medicare is planning to provide the public with comparative information about Nursing Home Quality. The measures are listed on the page that I am handing out to you now. Please take a few minutes to review them. Please keep in mind that the decision has already been made to provide this information to the public. What we need to learn from you is what is the best way to get this information to patients when they are making a nursing home decision.

→ *Pass out a document that lists all of the proposed measures:*

- ◆ physical restraints
- ◆ pressure sores
- ◆ weight loss
- ◆ infections
- ◆ pain management
- ◆ declines in activities of daily living
- ◆ use of anti-psychotic drugs without a psychiatric diagnosis
- ◆ managing delirium
- ◆ improvement in walking

1. How likely would you be to give this information to patients and families that needed to choose a nursing homes?

- ◆ Probe to determine
- ◆ When
- ◆ How
- ◆ In what format

2. What would prevent you from distributing this information?

- ◆ Probe about time constraints, concerns about liability, conflict of interest, concerns about data, e.g.
  - a. Some doctors are uncomfortable passing out this information because they are afraid of being held liable for the choice of nursing home. Is this a concern for you? Why or why not?
  - b. In many cases, gerontologists work in several settings including a private practice, a hospital, and a nursing home. In these cases, do you think some physicians might have a conflict of interest that would prevent them from giving out information about nursing homes?

3. How could we make it easier for you to provide this information to patients?

*Probe about preferred formats such as posters, brochures, etc.*

.If funding were limited, what would be the most effective way to support your efforts?

4. How do you think patients and their families would react to this information?

**IV. Closing**

5. Do you any additional comments and recommendations related to our discussion

**Thank you very much for your time and for your participation.**

## APPENDIX IX- Focus Group Discussion Guide for Discharge Planners

### Introduction

Thank you for joining us today. My name is \_\_\_\_\_ and I am here to talk to you about nursing home quality. I am working on a project for the federal government. The purpose of this project is to give consumers information about the quality of nursing homes in their area. We have invited you to this discussion because all of you have had experience discharging a patient into a nursing home.

Before we start today, I'd like to talk about a few things:

- ◆ I am interested in all of your ideas, comments, and suggestions. There are no right or wrong answers to the questions
- ◆ I'd like to hear from everyone
- ◆ All comments—both positive and negative—are welcome. Please don't worry about offending me with anything you might say—it's important that I know how you feel.
- ◆ Please feel free to agree or disagree with one another. We would like to have many points of view.
- ◆ Behind me is a one-way mirror. Behind it are people helping me today.
- ◆ This discussion is being video- and audio-taped, so that we can take better notes on what you all have to say. We may also show the tapes to others who are interested in the results but could not be here today. Before coming into the room you signed a release giving us permission to video/audio tape you during this discussion. All comments are confidential and used for research purposes only.
- ◆ I'd like this to be a group discussion, so you needn't wait for me to call on you. But please speak one at a time, so that the tape recorder can pick up everything.
- ◆ Your insights today will help guide the development of health communications materials—that is, messages about nursing homes that you might see on websites or in brochures, flyers or articles—that the federal government is doing for people like you.
- ◆ Does anyone have any questions before we begin?
- ◆ Please tell us your name and which hospital you work in.
- ◆ Now, please tell me a little about your current roles and responsibilities.
- ◆ Probe about case-load, paperwork, etc.
- ◆ Now, please tell me a little about your background. Were you trained as a nurse or social worker? How long have you worked as a discharge planner?

### **Description for Discharge Process**

Can one of you describe the discharge process for a person entering a nursing home. How does that process start? What happens next?....

*Probe to determine:*

- ◆ Steps in process
- ◆ Time frame
- ◆ Involvement of MD
- ◆ Involvement of family members
- ◆ Whether case load or other hospital duties impacts the discharge process.
- ◆ Do others in the room use a different process? If so, how is it different?
- ◆ What is the most difficult aspect of discharging a patient to a nursing home? Is there anything that could help you in this process?
- ◆ In your experience, what is the best way to discuss a nursing home decision with patients and their families?

### **Information Preferences**

- ◆ What information and advice do you currently provide to patients who are being discharged to a nursing home?
- ◆ Probe to determine messages/content, format, delivery.
- ◆ Do you refer patients and their families to other information or organizations for information about the quality of nursing homes?
- ◆ What types of information about nursing home quality do patients find most helpful or useful? Why?

### **Response to Nursing Home Measures**

Medicare is planning to provide the public with comparative information about Nursing Home Quality. The measures are listed on the page that I am handing out to you now. Please take a few minutes to review them. Please keep in mind that the decision has already been made to provide this information to the public. What we need to learn from you is what is the best way to get this information to patients when they are making a nursing home decision.

→ *Pass out a document that lists all of the proposed measures:*

- ◆ How likely would you be to give this information to patients and families that needed to choose a nursing homes?
- ◆ Some people think this information could help patients and their families to assess the quality of care they receive while in a nursing home. Would you encourage patients and their

families to periodically review this information after entering a nursing home? Why or why not?

- ◆ How do you think patients and their families would react to this information?
- ◆ How do you see yourselves using this information? Probe regarding use of information to build their own knowledge of NHQ
- ◆ What would prevent you from distributing this information? Probe about time constraints, inability to make recommendations, concerns about the age of the data, problems with access to the web, etc
- ◆ How could we make it easier for you to provide this information to patients?
- ◆ Probe about preferred formats, training needs
- ◆ If funding were limited, what would be the most effective way to support your efforts?