

IMPLEMENTATION OF THE MEDICARE MANAGED CARE CAHPS[®]

**Strategies for Reducing Barriers to Access and Increasing
Effective Use of Services by Vulnerable Medicare
Populations Enrolled in Health Plans**

FINAL REPORT

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Executive Summary

This report presents the findings from the Medicare Managed Care Qualitative Subgroup Analysis, the second facet of the Centers for Medicare & Medicaid Services (CMS) effort to assess the experiences and needs of four subgroups of the Medicare managed care population: disabled enrollees under the age of 65; seniors (over 65) in “frail” health; African American enrollees; and Hispanic enrollees. Round 1 of the subgroup analysis involved a quantitative assessment of the Medicare Managed Care Consumer Assessment of Health Plans Study (MMC CAHPS) survey, the instrument that CMS uses to monitor the quality of care and relative performance of Medicare managed care plans. Survey results from this first round of the analysis indicated the following:

- ◆ Enrollees who are eligible for Medicare due to disability, rather than age, have lower ratings of HMO performance across all dimensions of performance than other HMO enrollees;
- ◆ Aged enrollees who are in self-reported fair/poor health and who have limited independence also have lower ratings than other enrollees on most dimensions of HMO performance;
- ◆ Ethnic minority beneficiaries are more satisfied with their health plans overall when compared to other M+C enrollees; however, they are less satisfied specifically with the process of care and their ability to access needed services.

The goal of the qualitative subgroup analysis is to determine the basis for the above findings. The study team conducted literature reviews, site visits to eleven Medicare managed care plans, two rounds of Technical Expert Panel discussions, and numerous focus groups with subgroup beneficiaries in an effort to answer the following questions:

- ◆ What are the specific characteristics of each of these subgroups that may impact enrollees’ satisfaction with their health services under a managed care arrangement?
- ◆ How do beneficiaries in these four subgroups experience their care and access to services under a Medicare managed care plan?
- ◆ What can be done to improve enrollees’ levels of satisfaction and the quality of care that they receive?

A careful review of the findings from all four of the study methods suggests that, regardless of the individual’s age, race, or disability status, M+C beneficiaries viewed their plan experiences positively or negatively along three critical dimensions:

- ◆ Enrollee health status
- ◆ Enrollee financial status
- ◆ The enrollee’s ability to negotiate the barriers inherent in the managed care system

Specifically, enrollees expected that when they had a health condition requiring medical treatment, the managed care plan would cover the cost of the necessary services. When those

services were denied by the plan, individuals often required assistance either to negotiate the intricacies of a plan's bureaucracy (and get the decision overturned) or to locate an alternative, affordable source of treatment. It was this issue of assistance *qua* advocacy that emerged as most difficult for many of our focus group participants, but that also suggested the most possible solutions. Suggestions were made for solutions to come from the plans themselves, as well as from individuals outside of the managed care structure.

Plan-Based Solutions

Case Management and Disease Management

Given that the MMC CAHPS data evinced a direct correlation between plan satisfaction and enrollees' health status, one might anticipate that improvements in beneficiaries' health care would lead *indirectly* to an increase in plan satisfaction. Two programs instituted by several of the site visit plans would seem to lend themselves to enhanced consumer satisfaction. Case management, for example, aims to prevent downturns in an enrollee's health by ensuring that preventive and maintenance services are received in a regular and timely fashion. Similarly, disease management programs are oriented at stabilizing the enrollee's health by instituting strategies that can ameliorate the effects of chronic disease conditions. While both case management and disease management are utilized by M+C plans with an eye towards balancing quality care and financial sustainability, these programs should also maintain or improve enrollees' health and, by extension, their satisfaction with their plans.

Clarity in plan benefits

A second concern expressed by beneficiaries was that when they did have a need for services, it was not always clear from the plan materials the benefits for which they were eligible. In some cases, they said, the plan information was in dense, booklet form, and not easily understood by anyone without a law degree; more often, however, enrollees wanted information in a format that was clear, simple, and easy to understand. While beneficiaries who were not native speakers of English requested plan information in their native languages, the issue actually transcended traditional notions of "cultural competence." For example, individuals with visual impairments requested that plan information and updates be made available in auditory or Braille formats. And numerous focus group participants suggested that enrollees with cognitive challenges needed to receive benefits information via forms or processes that accommodated those impairments. The request was thus not just that plans disseminate benefits information in a culturally appropriate way, but in ways that could be accessed and understood by enrollees with any number of characteristics and challenges.

In addition, focus group participants in almost every site expressed their belief that, contrary to Medicare policy, plans were changing their benefits structure mid-year. A more likely explanation, however, is that beneficiaries – uncertain as to who was actually sponsoring their health insurance – were confusing their Medicare plans (which had not changed) with their employer-sponsored plans (whose benefits structures can change throughout the year). Beneficiaries were less upset by the mid-year changes than by the fact that they often learned of the alterations after they called to schedule an appointment with a provider (no longer in the plan) or to receive a previously-covered treatment. This finding reinforces their previous request

that any and all changes to plan benefits be conveyed to enrollees in an easily understood (see above) manner and via a format that can be readily referenced throughout the plan year.

Reasonable response time on phone

Consonant with the above point, beneficiaries reported that when they had a question about their benefits and called the toll-free number to get additional information, the processes through which they had to go to get their questions answered were difficult and involved. In some cases, they said, they had to wander through a maze of push-button options (“for information about X press 1”), sometimes only to get punted to an answering machine or kicked out of the phone queue altogether. Individuals with various cognitive impairments, we were told, had significant difficulties trying to negotiate the option maze, which required a level of patience and attention to detail and sequencing that many beneficiaries do not have.

While many enrollees said that they could deal with the telephone hurdles, they were loathe to do so when they failed to reach a “live” person in a reasonable amount of time. Long waiting periods “on hold,” or even abbreviated waiting times to leave an answering machine message were deemed inadequate by most of the participants, who wanted their questions answered in a more timely fashion. Stricter monitoring of help lines, or even more stringent requirements for responding to incoming calls, may help to alleviate some of these concerns.

Plan-Sponsored Peer Communication Events

The focus groups provided the research team with numerous opportunities to observe the benefits that naturally accrued to individuals who participated in these interactions. Although each group developed its own unique dynamics, in almost every instance certain group participants took on the role of peer supports for others. Sometimes it was a simple dynamic, whereby individuals shared their experiences and their respective approaches to solving a common problem. Just as often, though, empowered members of the group took up “the cause” of their less-empowered colleagues, sharing names of physicians who were particularly well-liked, offering ideas about where enrollees could go for possible financial assistance, and even suggesting where individuals might be able to receive affordable treatment when they needed services not covered by the HMO. Focus group participants widely noted the power in the group process, and suggested that plans support regular get-togethers by enrollees for sharing of ideas, experiences, and socialization.

Advocacy Outside the Plan

One of the most important lessons offered by the beneficiaries was that because of cognitive or other challenges, many of them required additional support or advocacy in order to receive the medical care that they needed. In one of the site visit plans, beneficiaries received a membership card that had a picture of their “Dedicated Customer Service Representative.” This Representative was promoted by the plan as the individual who “could answer any questions” and could assist the beneficiary with getting needed services. Given the competing interests of the beneficiaries and the plans – i.e., that both parties are looking to the other to absorb the cost of health services – it would seem important for the advocate to be someone *not* directly linked to the plan itself. One promising example was found at one site visit, where plan enrollees had

access to an ombudsperson whose job was to report not to the plan, but to the county health department.

Conclusions

Overall, the findings from the focus groups and the other three study methods seem to suggest that Medicare managed care beneficiaries *as a group* can be viewed as a vulnerable population. Despite the fact that many were in relatively good health, they recognized that their advanced age carries with it the potential for a serious health crisis, which in turn could mean financial destitution. They thus viewed Medicare HMOs as offering the possibility of striking the delicate balance between good health care services and financial integrity – so long as the plans came through during the inevitable health crisis. CMS’ efforts to monitor the M+C plans and enrollees’ satisfaction must walk this same fine line, ensuring that reasonable health care service is delivered to beneficiaries in a cost-effective manner. The suggestions offered in this report may serve as a first step towards understanding the perspectives of the M+C enrollees, as well as recognizing possible directions that may lead to improvements in the way Medicare beneficiaries are served.

Chapter I – Introduction and Overview

In 1999, approximately 15 percent of all Medicare beneficiaries – about 6.3 million individuals – were enrolled in Medicare Managed Care plans (HCFA 1999). The Centers for Medicare & Medicaid Services (CMS, formerly known as the Health Care and Finance Administration (HCFA)) is responsible for monitoring and providing oversight to Medicare+Choice (M+C) organizations to ensure that Medicare beneficiaries receive appropriate care at an acceptable level of quality. One component of CMS’ monitoring and oversight efforts is the Medicare Consumer Assessment of Health Plans Study (CAHPS) survey. Survey results from the Medicare Managed Care (MMC) CAHPS provide CMS with information that can be used to monitor the quality of care and relative performance of Medicare managed care plans. The results also provide information to health plans on their own performance that may help them to identify problems and improve the quality of care and services that they provide to Medicare beneficiaries.

Despite the intrinsic value of these survey findings, CMS staff recognize that such broad assessments across all of a plan’s enrollees may obscure differences in the experiences of certain subgroups of the population, especially groups who have characteristics that may make it difficult for them to obtain services. Of particular concern are beneficiaries with exceptional health needs, such as the “frail” elderly and disabled persons, who, some studies have suggested, may experience worse health outcomes in managed care settings. CMS also is concerned about those enrollees who may experience barriers to care as a result of cultural differences, language barriers, or other factors, such as certain racial or ethnic subgroups of the Medicare population. As managed care continues to expand into the Medicare marketplace, CMS increasingly will need to be able to monitor these special groups’ experiences and satisfaction with their plans.

The MMC CAHPS subgroup analysis represents CMS’ effort to make an initial assessment of the experiences of various subgroups of the Medicare managed care population. Under this endeavor, CMS contracted with Barents Group of KPMG Consulting and Westat to conduct a two-part study on enrollees’ experiences. The first year (Round 1) of this project involved a quantitative assessment of MMC CAHPS survey results and had two primary objectives:

- ◆ To determine whether there are differences in plan ratings, both overall and for specific dimensions of HMO performance, between selected subgroups of the Medicare population; and
- ◆ To the extent possible, to identify variations among HMOs, by region, market characteristics, and organizational characteristics, that may be associated with differences in plan rating reported by selected subgroups.

Key findings of the Round 1 analysis included the following:

- ◆ Enrollees who are eligible for Medicare due to disability, rather than age, have lower ratings of HMO performance across all dimensions of performance than other HMO enrollees;

- ◆ Aged enrollees who are in self-reported fair/poor health and who have limited independence also have lower ratings with most dimensions of HMO performance than other enrollees;
- ◆ Ethnic minority beneficiaries are more satisfied with their health plans overall when compared to other M+C enrollees; however, they are less satisfied specifically with the process of care and their ability to access needed services.

Figure 1 – MMC CAHPS Survey Responses by Subgroup

Survey Question	Subgroup				Overall Across Entire Sample
	Disabled Under Age 65	65+ in Fair/Poor Health	Hispanic/Latino	Non-White	
Question with rating: 0=Worst to 10 - Best	Mean	Mean	Mean	Mean	Mean
Overall satisfaction with health plan	8.1*	8.5*	8.8	8.7	8.7
Satisfaction with personal doctor or nurse	8.6*	8.6*	8.8	9.0*	8.8
Satisfaction with specialist	8.4*	8.5*	8.6*	8.6*	8.7
Satisfaction with all doctors and other health professionals	8.3*	8.5*	8.8	8.8	8.8
Questions with rating: 1 = Never to 4 = Always	Mean	Mean	Mean	Mean	Mean
Wait more than 30 minutes (REVERSE CODING 1=Always...)	3.3*	3.3*	3.2*	3.3*	3.4
Office staff courtesy and respect	3.7*	3.8*	3.8*	3.8*	3.8
Doctor respect	3.5*	3.6*	3.7	3.7	3.7
Spend enough time	3.4*	3.4*	3.5	3.5	3.5
Gets tests or treatment	3.4*	3.5*	3.5*	3.5*	3.6
Approvals for payments without time or energy	3.0*	3.0*	2.8*	2.7*	3.1
Get information from customer service	3.1*	3.2*	3.2*	3.2*	3.3
Questions with rating: 1 = Yes and 0 = No	% Yes	% Yes	% Yes	% Yes	% Yes
Easy to get referral	.81*	.87*	.87*	.87*	0.9
Get equipment without time or energy	.65*	0.81	.76*	.75*	0.81
Get therapy without time or energy	.62*	.81*	.72*	.76*	0.83
Get home health care without time or energy	.56*	.67*	0.69	.61*	0.71

* These Diff. % values are significantly differently from non-subgroup values at the .05 level

While there are numerous possible explanations for the results that obtained in the Round 1 analysis, this facet of the study was limited in its ability to explain the quantitative findings. One could speculate as to why the disabled population is less satisfied across the board, or how linguistic and cultural factors negatively impact ethnic minorities' ability to access needed services...but it would be speculation. Thus, the intent of Round 2 of the subgroup analysis was to determine the "why" behind some of the above findings. What are the specific characteristics of each of these subgroups that may impact enrollees' satisfaction with their health services under a managed care arrangement? Alternatively, how do beneficiaries in these four subgroups experience their care and access to services under a Medicare managed care plan? And, finally, what can be done to improve enrollees' levels of satisfaction with their plans and the quality of care that they receive?

The objective of this Round 2 report is to present findings from the numerous components of the qualitative subgroup analysis. In the next chapter, we present a description of the various research methods we used to explore the above questions. In Chapter 3, we offer a rich description of study findings. A particular emphasis in this chapter is on understanding the implications of the "subgroup" divisions and discussing why that fourfold division may not be the most meaningful categorization within the managed care framework. In the final chapter, we summarize the study findings and briefly discuss their implications for on-going and future research and policy efforts.

Chapter II – Methods

Round 1 of the MMC CAHPS subgroup analysis focused on two broad categories of beneficiaries: M+C enrollees with “exceptional health care needs,” which was operationalized as seniors (over 65) in self-described “fair” or “poor” health, disabled persons under the age of 65, and persons with limited independence; and “vulnerable populations,” which included African American beneficiaries, Hispanic M+C enrollees, and beneficiaries with an 8th grade education or less. In an effort to limit the variables involved, this second round of the subgroup analysis aimed to learn about the unique health needs and care experiences of only four of the previously defined sub-populations:

- ◆ Beneficiaries over 65 in self-described fair or poor health (“frail elderly”)
- ◆ Disabled beneficiaries under 65
- ◆ African American beneficiaries
- ◆ Hispanic beneficiaries

It is important that the reader recognize at this juncture that CMS and the research team started with the premise that these four groupings occur naturally (and mutually exclusively) within the social world, and therefore are subject to empirical investigation. Both the Literature Reviews and the Technical Expert Panel (TEP) meetings (see below) operated from this assumption, and thus examined the unique health needs of seniors in poor health and disabled individuals (ethnicity notwithstanding), and the needs of African American and Hispanic M+C enrollees (health status and age notwithstanding). What the team learned during the site visits to plans, however, was that – as with any system of classification – the parameters the researchers used to delineate these four groups were in some sense arbitrary. That is, although CMS and the researchers were concerned with four distinct and seemingly unique subgroups, the M+C plans delineated their enrollee population using a different classification scheme. In addition, the focus groups sought to ascertain how beneficiaries categorize, and thus make sense of, their own experiences under Medicare managed care: What dimensions of their lives do they believe interface with the managed care system and preclude them from accessing needed services? What we learned from the beneficiary discussions was that our four “groups” are not necessarily mutually exclusive, i.e., there are African American seniors in poor health, disabled beneficiaries who are Hispanic, white seniors in good to excellent health, and so forth. Moreover, beneficiaries viewed not only their health status, but also other issues as being salient to receiving (or not) the care that they required. These distinctions in classification will take on greater importance in Chapter 3, when we look at the findings from the different research methods.

Literature Reviews

Members of the Barents Group commenced the second round of the subgroup analysis by conducting a comprehensive review of the literature with this key question in mind: “What are the health care needs and barriers facing each of four study populations?” The team examined journal articles, research reports, and other literature to determine the predominant health issues in each group (e.g. high incidence of diabetes in African Americans), strategies that plans or physicians have used to address these group-specific issues (e.g., disease management

programs), and recommendations for approaches (e.g., cultural competency training) that might further improve the health status of these subgroup members. A draft report was prepared for each of the four subgroups, and submitted to the Project Officer for review and comment. Drafts were also submitted to members of the respective Technical Expert Panels (TEPs) for review. Feedback from TEP members was accommodated in the final draft of each report (see below).

Technical Expert Panel Meetings

Two rounds of Technical Expert Panel (TEP) meetings were convened for each of the four study populations. The TEP meetings were intended to inform and validate the project staff's understanding of the complex needs and barriers facing these subgroups, while also serving as a sounding board for improving the preliminary literature reviews, the site visit protocol and planning, and the focus group design. During the months of April and May 2000, the Barents Group convened the first round of TEP meetings (one meeting was dedicated to each of the subgroups) to discuss health care access, satisfaction, and quality of care issues related to four subgroups of the Medicare managed care population. The first-round meeting objectives included the following:

- ◆ Identification of special health care needs and barriers to access for each of the four subgroups;
- ◆ Discussion of managed care strategies and/or approaches to caring for the four subgroups; and
- ◆ Provision of feedback on the preliminary literature review, the site visit protocol and planning, and the focus group planning.

Each TEP was one day in duration and was composed of 4-6 members who had expertise and familiarity with the study population. In addition, in selecting members of the TEPs, an effort was made to obtain a cross-section of representatives from academia, from Medicare + Choice HMOs, member advocacy groups, and community-based organizations. The first round of TEPs was held prior to the Medicare + Choice HMO site visits and focused on the health care needs and barriers of the respective study populations.

During the month of December 2000, after the site visits were conducted, CMS and the Barents Group convened Round 2 of the TEP meetings. With a few exceptions, TEP members who participated in the Round 1 TEPs were the same as those who participated in Round 2. During this second round of TEPs, participants were briefed on the site visit findings, and then were asked to help develop a list of actionable items that CMS could present as recommendations to Medicare + Choice HMOs for improving member access and satisfaction. A summary report was completed for each group in both rounds of the TEPs (eight reports in all) and submitted to the CMS project officer for review and comment.

Visits to M+C Plan Sites

An additional aspect of this evaluation involved conducting site visits and preparing case studies of health plans that were more successful than others in enrolling and serving selected

subgroups. Health plans were primarily chosen on the basis of their composite scores obtained on the 1998 CAHPS survey questions (all questions are included in Figure 1 on page 3) and as reported by Barents Group of KPMG Consulting.¹ Weighting of composite scores was as follows: 0.25 for *Overall Plan Satisfaction* (4 questions); 0.45 for *Process of Care* (6 questions); and 0.30 for *Access to Care* (4 questions). Plans were then divided into two categories: Category 1 included those with a relatively high concentration of one or more of the subgroups under investigation and a high weighted composite score for the CAHPS survey questions. Category 2 included those with a relatively high concentration of one or more of the subgroups under investigation and a low weighted composite score for the CAHPS survey questions. There were eight plans in Category 1 and three plans in Category 2. Our original intent was to select a total of twelve plans: eight in Category 1 and four in Category 2. However, four of the originally selected plans refused to participate in the study and were replaced with three similar plans. In addition to considering relatively “good” and relatively “fair-poor” composite scores as selection criteria, several additional variables were also considered in arriving at the final selection of health plans: geographic diversity; profit status; chain vs. independent HMO; years of experience; type of health plan model (e.g., network vs. group vs. staff); number of respondents (“cell count”); and the number of times a health registered a “score” for each of the four subgroup categories.

The team developed a detailed site visit protocol that aimed at obtaining information on HMO organizational structure, utilization management and control practices, case management approaches, cultural competency (e.g., language capabilities, outreach and education activities), and special programs that are designed to serve the needs of specific subgroups of the Medicare population. Over a four-month period, the study team conducted two-day site visits to eleven different Medicare + Choice HMOs. Summary reports were completed for each site visit, and submitted to the Project Officer for review and comments.

Focus Groups with M+C Enrollees

While CMS recognized the value of the information collected through these first three research methods, the Project Officer was also interested in hearing from the M+C beneficiaries themselves. Specifically, what are the perceived health care needs and the experiences of Medicare Managed Care enrollees who are members of each of the four subgroups? The focus group component of this study underwent several iterations before being implemented. Following the first round of TEP meetings, the Barents-Westat evaluation team had decided not to conduct groups with under 65 and disabled beneficiaries because of the tremendous diversity of disability categories that might be represented, and the concomitant range of issues (e.g., physical versus cognitive disabilities) that might emerge as a result of the various health care needs. Similarly, evaluators had proposed not to conduct groups with elderly individuals in self-described fair or poor health due to the possible severity of their health conditions and the difficulties they might face getting to/from and participating in a discussion group. The original focus group plan thus proposed to conduct ten focus groups with the two “vulnerable” populations - six groups with African American beneficiaries and four with Hispanic beneficiaries - at eight of the M+C markets that had received a site visit from the team. In

¹ Barents Group of KPMG Consulting. *Implementation of the Medicare Managed Care CAHPS: Final Report on Subgroup Analysis, Round 1*. February 2000.

addition, because of continued concerns about members in poor health having difficulty with attendance and participation, it was decided that all ten focus groups would be conducted with beneficiaries in self-described “good” or “excellent” health.

Feedback from the members of the second round of TEP meetings prompted a reconsideration of several aspects of the focus group study design. First, TEP members suggested that beneficiaries in *all four* subgroup categories should have the opportunity to voice their opinions about their Medicare managed care plans. This was believed to be particularly important for the under 65 disabled beneficiaries, because as the Round 1 analysis had shown, enrollees who are eligible for Medicare due to disability (rather than age) had lower ratings of HMO performance across all dimensions of performance when compared to other HMO enrollees (Round 1 report, page 32 – Feb. 15, 2000).

Secondly, members of the African American TEP noted the significant overlap between ethnic identity and health status in this country – specifically, that members of ethnic minorities generally have a lower health status than their white counterparts. The panel thus suggested that we not exclude potential participants who reported a lower health status, but actively recruit such individuals in order to understand their unique health care needs and experiences. Moreover, we were encouraged to host comparison groups – one with white beneficiaries in poor health, and one with ethnic minorities in good/excellent health – so that we would be able to discern whether ethnicity or health status was the source of difficulties with a managed care plan.

Finally, Hispanic TEP members suggested that the recruitment of Hispanic focus group participants might be more successful if the study team enlisted the logistical support of a community-based organization (CBO), ensured that our focus group moderator was both bilingual and bicultural, and provided food for participants that was culturally appropriate.

We took into account all of these suggestions as we redesigned our focus group study. First, the revised plan increased the total number of focus groups that we would conduct (from ten, to twenty) to ensure that we heard from members of all four subgroups and from individuals with varying health statuses. However, to offset the increase in the number of groups and enhance the feasibility of the endeavor, the evaluators reduced the number of market areas from eight to four, focusing on sites that we believed would provide us insights into any relevant regional differences in Medicare managed care plans and members’ experiences.

In addition, we designed a focus group plan that would allow us to distinguish the effects of ethnicity from the effects of age and/or health status. While beneficiaries in all four categories included in the subgroup analysis experience challenges to the receipt of adequate health care, these *categories* do not describe mutually exclusive *groups*. That is, two individuals may claim the same ethnicity, but see themselves as “not alike” because their respective health statuses have them positioned differently with regard to the medical system. Conversely, beneficiaries may have different ethnic identities (e.g., white and Hispanic), but self-identify as members of the same “group” because of a shared medical condition (e.g., diabetes). For example, an African American senior and Caucasian senior may see themselves as members of different “groups” if asked to describe their experiences living in Birmingham, Alabama. But if they are asked to

describe challenges they have faced getting medical care for a serious cardiac condition, these two individuals may find a common identity around their shared experiences.

We thus determined the desired composition of our focus groups with this social phenomenon in mind. More specifically, we established the group parameters along three key axes: age (over 65 *versus* under 65), ethnicity (African American, Hispanic, or Caucasian), and health status (“frail” *versus* “disabled” *versus* “good-to-excellent” health). The geographic location and dates of the groups, their participant composition, moderators, and facility locations are listed in the table on the next page.

Figure 2 – Description of Focus Groups

Birmingham, Alabama			
Date	Group Composition	Facilitator(s)	Location
May 8	Under 65 Disabled**	Robins and Myers	Jewish Community Center
	White Elderly Fair-Poor	Robins and Myers	Connections Facility
May 9	African American Elderly Fair-Poor	Lee and Robins	Connections
	African American Elderly Good-Excellent	Lee and Robins	Connections

Miami, Florida			
Date	Group Composition	Facilitator(s)	Location
May 11	Hispanic Elderly Fair-Poor	Saenz	Little Havana Activities & Nutrition Center (LHANC)
	Hispanic Elderly Good-Excellent	Saenz	LHANC
May 14	White Elderly Fair-Poor	Robins and Myers	Strategy Research Corp.
	Under 65 Disabled**	Robins and Myers	Strategy Research Corp.

San Antonio, Texas			
Date	Group Composition	Facilitator(s)	Location
May 16	African American Elderly Fair-Poor	Lee	Creative Consumer Research (CCR)
	African American Elderly Good-Excellent	Lee	CCR
May 17	White Elderly Fair-Poor	Robins and Myers	CCR
	Under 65 Disabled**	Robins and Myers	CCR
May 18	Hispanic Elderly Fair-Poor	Saenz	CCR
	Hispanic Elderly Good-Excellent	Saenz	CCR

New York City			
Date	Group Composition	Facilitator(s)	Location
May 30	African American Elderly Fair-Poor	Lee	New York Focus (NYF)
	African American Elderly Good-Excellent	Lee	NYF
May 31	Hispanic Elderly Fair-Poor	Saenz	NYF
	Hispanic Elderly Good-Excellent	Saenz	NYF
June 1	White Elderly Fair-Poor	Robins and Myers	NYF
	Under 65 Disabled**	Robins and Myers	NYF

** Individuals in these groups represented a range of ethnic identities.

In order to create a pool of potential group participants and facilitate the recruiting process, the evaluation team used data from the CAHPS super sample. The super sample is used to disguise the identity of the true sample members from the health plans when researchers request telephone numbers. On average, a super sample of about 3,000 beneficiaries is selected for each participating health plan, with the true sample of 600 imbedded. For the CAHPS survey, we request telephone numbers for all persons in the super sample. Thus, for the selected plan in each market area, the team was able to use the data set to get names, addresses, and phone numbers of plan enrollees. The data also include a field for “date of birth” that allowed us to determine which enrollees were over 65 (traditional Medicare “seniors”) and which individuals were “under 65” and therefore *de facto* part of the cohort who qualify for Medicare due to disability. In addition, the super sample contains a field for “ethnic identity” that allowed us to sort the beneficiaries by reported ethnicity (i.e., we developed a list of African American senior beneficiaries for each relevant plan, a list of Hispanic senior beneficiaries, etc.). All potential recruits were mailed a letter from CMS outlining the purpose, benefits, and relative risks of the study, and letting these individuals know that they *might* receive a phone call requesting their voluntary participation in the study.

Recruiters at each focus group facility were sent these lists of beneficiaries, along with a screening form that asked respondents to verify certain key information, such as enrollment in a particular Medicare managed care plan, age, and ethnic identification. Respondents were also asked to self-assess their health status using a five-point scale where **1** = *poor*, **2** = *fair*, **3** = *good*, **4** = *very good*, and **5** = *excellent*. For the purposes of the project, all individuals who were over 65 and reported a health status of fair or poor were defined as “frail elderly.” The working assumption of the evaluators was that these individuals would require greater attention from the health care system than would those beneficiaries who reported a health status of **3** or higher. Facilities recruited enough potential participants to ensure that between 8 and 10 enrollees came to each focus group.

With the exception of the one group at the Jewish Community Center in Birmingham, and the two groups at the Little Havana Activities and Nutrition Centers of Dade County in Miami (see tables, previous page), all groups were held at professional focus group facilities. While the evaluators recognized the benefits of working through CBOs in each community, it was not feasible for the team to organize and facilitate all of the groups in this manner. The professional facilities were able to provide us with recruiting services, video and audio recording capabilities, transportation support and food for the participants, as well as other amenities (e.g., telephones, handicapped accessible restrooms, etc.). We believe that the use of these professional services where possible helped to enhance the overall success of this project.

Finally, the evaluation team endeavored to provide culturally competent and consistent moderation across all of the sites. African American moderator Brenda Lee, working out of Riva Associates in Bethesda, Maryland, was contracted to provide facilitation services for each of the six groups conducted with African American beneficiaries. Laura Saenz, a bilingual/bicultural (Mexican-American) facilitator whose Latino-oriented marketing company is located in Chicago, Illinois, moderated all of the Hispanic groups. Finally, Westat employees Cynthia Robins and Mary Anne Myers facilitated the four groups with elderly Caucasians and the four groups with disabled beneficiaries under the age of 65.

Limitations of the Study Design

There are several caveats that the reader should keep in mind as s/he peruses this report and contemplates the noted implications of our findings. First and foremost, the evaluation teams recognize the incontrovertible evidence that there are pervasive health disparities in this country, some of which clearly fall out along ethnic lines. However, there is no clear evidence that points to a single mediating factor, or even a set of such factors. Although institutional racism² is seen by many scholars to be a continued and unfortunate facet of American culture, the role of race in health disparities quickly becomes confounded with the role of social class, financial well-being, and even individual health status. Thus, the extent to which we would be able to identify ways in which Medicare managed health care plans aimed to override such far-reaching issues will be limited at best.

Secondly, the reader should be cautioned about generalizing from the sample of health plans used in this study to the broader set of Medicare managed care plans. Not only is our sample size (n=11) of selected health plans small, but, within this group, there were even smaller numbers of different health plan models (e.g., group, staff, IPA, network, or mixed models) and profit-status types (e.g., for profit versus not-for-profit). We thus are able to describe some common ways in which these eleven plans attempted to meet the needs of subgroup members, but we cannot say whether “all group model” plans or “all network model” plans employ similar approaches. Perhaps a future study will be able to ascertain how different plan models devise and implement strategies for serving specific subgroups.

Third, as suggested previously (and as will be discussed further), the four subgroups selected for this study are not so much “corporate groups” in the sociological sense as they are *categories* with which people *identify or are identified*. That is, as outsiders, we have classified sets of people as “alike” based on the ethnic status they reported on a survey form, or the health status that they reported on the day our recruiters happened to phone them. It is critical to recognize, however, that the dimensions along which we have defined people’s experiences as salient (e.g., ethnicity, “frail” health status, etc.) may not be the dimensions that the beneficiaries themselves find meaningful. The way in which we set up our focus groups did suggest salient dimensions of beneficiaries’ experiences (see Chapter 3) that we had not anticipated. We recognize, however, that we still may have overlooked aspects of these individuals’ lives that they view as particularly meaningful with respect to their health care. Further research along additional critical dimensions (e.g., beneficiary gender, poverty status) may provide us with important insights into other factors that impact these individuals’ experiences.

Although this study is limited in scope by the aforementioned and other factors, it nevertheless has produced some interesting preliminary findings, several of which are worthy of further exploration and research. These findings, their significance, and potential utility are discussed in more detail in the following chapters.

² Institutional racism is generally viewed as the indirect exclusion of ethnic minorities from full social participation as the result of discriminatory social policies, and not the deliberate actions of any individual.

Chapter III – Findings

The Round 1 analysis of the MMC CAHPS survey data, as noted previously indicated that there are differences among the selected subgroups in their assessment of how well they are served by HMOs, relative to other M+C plan enrollees. For example, enrollees who are eligible for Medicare due to disability, rather than age, have lower ratings than other HMO enrollees do across all dimensions of plan performance. Seniors in self-reported fair/poor health who have limited independence also have lower ratings than other enrollees do on most dimensions of HMO plan performance.

In theory, one might anticipate that the utilization management process that is an integral part of managed health care would have positive consequences for beneficiaries, since central management would provide enrollees with well-coordinated, highly integrated services. The analyses performed for Round 1, however, indicate that such individuals are no more satisfied with the care that they receive in HMOs than are their counterparts in fee-for-service. Moreover, they are significantly *less satisfied* with the process of care and access to services in HMOs than are those within fee-for-service. These findings suggest several possible explanations: that HMOs may not be providing the coordination and integration of care that the research team expected; that the utilization review process imposes additional burdens on those with exceptional health care needs; or, it might suggest that beneficiaries resent *any* restrictions/limits on their access to care or providers, limits which are part of the essence of “managing care.”

The study also examined the experiences of what we termed “vulnerable” subgroups, and learned that, counter to what we had anticipated, each of these groups is *more satisfied* overall with their health plans than were other HMO enrollees. However, both Hispanics and non-White HMO enrollees were less satisfied than other HMO enrollees with dimensions of the process of care and with their ability to access to services. The lower ratings of process and access could be the result of cultural differences that would require special efforts by HMOs to explain and assist these groups with receiving necessary care. In light of the strong correlation between ethnicity and health status in this country, however, and the fact that the analysis also did not control for respondent health status, it is possible that these lower ratings are reflective of each group’s overall lower health status and the barriers to care that persons with exceptional health care needs experience within an HMO system of care.

Because the Round 1 results are only descriptions of statistically significant differences in enrollee satisfaction, efforts to account for these differences can be only speculative at best. Thus, the aim of Round 2 of the subgroup analysis was to try to explain some of these differences using the four qualitative methodologies described in the previous chapter. Yet in reviewing the results that ultimately obtained from each methodology, we are faced with a challenge that was presaged in the previous chapter: namely, that the classification schemes and epistemological assumptions underlying each of these methods are in many respects quite different from one another. For example, and as noted previously, both the literature reviews and the TEP meetings were undertaken on the premise that the four subgroups in this study are distinct groups of beneficiaries who have unique health care needs. These methods thus aimed to document what the needs are for each group, and then to ascertain the optimal strategies that managed care plans can implement to address the four sets of issues.

Although the site visits to M+C plans started from this same assumption, that assumption ultimately was debunked when the evaluation team talked with plan representatives. The goal of a managed health care plan, they said frankly, is to (*balance* the goals of providing quality care while simultaneously managing the financial risk of delivering such care, just as has always occurred in the fee-for-service world. They noted that while profitability is essential for plans to continue operating, if profit isn't balanced with the requirements of delivering quality care, then the plans won't stay in business very long. The message they offered was that quality and fiscal prudence are both essential; when programs are designed and implemented correctly, quality principles can drive profitability. Many site visit interviewees recognized this and subscribed to the old adage, "manage the care, not the cost," meaning, if you do the right thing, the costs will take care of themselves. While age, disability status, or ethnicity *may* correlate with an individual's physical well-being and thus with the enrollee's potential risk to the plan, HMOs manage financial risk by tracking their enrollees' health status, not these other demographic characteristics. Thus, the world-taken-for-granted of the evaluation team (the salience of the four subgroups) did not match the worldview of the managed care plans and, to a certain extent, obfuscates the many financial issues involved in the health insurance industry.

Finally, the ethnographic researchers who established the focus group design and discussion protocol had the benefit of the above findings at their disposal, and thus worked from the assumption that we could not know *a priori* the salient dimensions of enrollees' experiences in Medicare managed care. Enrollees might feel that their ethnic identity or age was a critical factor in getting their health needs met (or not); but they also might describe other characteristics that they believed to be important, such as their gender or their state of financial well-being. In operating from the basis of narrative analysis, we thus designed the focus groups in such a way as to allow participants to define the parameters of their experience, rather than to have those dimensions (in effect, their "group membership") established in advance by the research team.

The challenge to understanding the study findings, therefore, is to recognize that there are three worldviews that were brought to bear on the problem. One is the worldview of CMS and the research team, which is concerned with the needs and issues of four predetermined subgroups. Another is the perspective of the Medicare HMOs, whose concerns are the management of financial risk related to beneficiary health status. Finally, there is the worldview of the beneficiaries themselves, whose understanding of their health needs, their financial status, and the objectives of managed care combine to create a rich – if somewhat complex – model of barriers to care within Medicare managed care. We examine the findings from each perspective accordingly.

Needs of the Four "Subgroups"

In seeking to determine the specific needs of and barriers to care faced by each of the four subgroups, the literature reviews and the TEP discussions produced what amounted to variations on a theme. Specifically, both methods defined the *unique* needs of each group along roughly the *same* parameters: health conditions specific to each group; relevant financial issues; and the need for medical personnel who are sensitive to the distinct characteristics of each population. Thus, while each group was determined to have distinctive characteristics, the dimensions along

which those distinctions were realized were the same across the four groups. We discuss each of these dimensions in turn, below.

Health Conditions

Each of the four subgroups examined for this analysis evinced either a distinctive pattern of illnesses or a prevalence rate of a specific illness that is higher than the rest of the Medicare population. Seniors in poor health, for example, often must contend with multiple chronic conditions, many of which are associated with the aging process. Among such conditions are Alzheimer's, osteoporosis, and cardio-obstructive pulmonary disease (COPD). Seniors may also require support for pain management in order to cope with such debilitating conditions as shingles, neuralgia, or broken bones secondary to osteoporosis. Finally, our findings indicate that the frail elderly and other chronically ill populations frequently seek medical treatment in an effort to *maintain* or *stabilize* their quality of life, rather than generate substantial improvements in outcomes. There was a call for M+C plans to shift their goals to match the reality of this beneficiary subgroup, so that approved treatments are not just those that lead to "improved outcomes," but also those that support "maintenance" or "stability" in the beneficiaries' quality of life.

Specific needs for the under 65 disabled population were also indicated in the literature reviews and TEP discussions. Importantly, the findings suggest that the "disabled subgroup" does not comprise one population, but includes individuals with physical as well as mental disabilities. In fact, in contrast to the other subgroups, individuals in this subgroup display disproportionately high rates of cognitive difficulties, since many qualify for disability because of mental impairments. In 1996, more than one in five individuals who became eligible for disability qualified due to mental disorders or mental retardation. Over half of all under-65 disabled have problems with mental functioning, which is three times the rate among seniors.³⁴ Additional evidence suggests that mentally disabled individuals have a definable set of unique health care needs that the physically disabled do not necessarily have, and demonstrate significant differences in survey results for access to care and satisfaction than those individuals with only physical disabilities.⁵

Elderly African Americans are confronted disproportionately with several health conditions that negatively impact their lives, and should be considered by health care organizations and physicians when developing targeted health education, preventive care, or disease management programs. For example, in addition to what appears to be an increased risk for developing Alzheimer's disease⁶, African Americans have higher cancer mortality rates than their white counterparts.⁷ In 1992, the age-adjusted mortality rate for all cancer deaths was 32 percent

³Henry J. Kaiser Foundation, *The Faces of Medicare: Medicare and the Under-65 Disabled*. July, 1999.

⁴The environment of disability income policy: Programs, People, History, and Context, Interim Report of the Disability Policy Panel, National Academy of Social Insurance, 1996.

⁵Rosenbach, M. "Access and Satisfaction within the Disabled Medicare Population." *Health Care and Financing Review*, 1995: 17(20): 147.

⁶Tang MX, Stern Y, Marder K, Bell K, Gurland B, Lantigua R, Andrews H, Feng L, Tycko B, Mayeux, "The ApoE-epsilon4 Allele And The Risk Of Alzheimer Disease Among African Americans, And Hispanics." *JAMA*, 279:10 (March 11, 1998): 751-5.

⁷According to the American Cancer Society, the cancer mortality rates in African Americans increased 62 percent among males and 16 percent among females between the years 1962 and 1992.⁷ This compares to 19 percent and

higher for African Americans (224.8 per 100,000) than for all races combined (172.2 per 100,000).⁸ The leading cause of death for African Americans in the U.S. is coronary heart disease.⁹ Yet, despite higher mortality and morbidity from cardiovascular diseases, African Americans are less likely to undergo treatment for their condition.¹⁰ They are also less likely to be seen by a cardiovascular specialist—even when enrolled in Medicare or Medicaid.^{11,12}

African Americans also bear a disproportionate share of certain chronic, disabling conditions such as diabetes and hypertension. As a population, African Americans are 1.7 times more likely to have diabetes than whites.¹³ One out of every four African-American women over 55 years of age has diabetes and 25 percent of all African Americans between the ages of 65 and 74 have diabetes.¹⁴ Morbidity and mortality rates due to hypertension-related conditions are three to five times higher for African Americans than for whites.¹⁵ Further illustrating the burden of hypertension on African Americans is the high rate of stroke mortality in certain areas of the country that are heavily populated by this population. For the past 50 years, the southeastern United States has been known as the “stroke belt.” Some researchers have posited race as a leading confounding factor in the geographic variation of the incidence of and mortality rate from stroke.^{16,17} However, whites in the southeast also suffer disproportionately high hypertension-related mortality, and African Americans in the western and northeastern U.S. do not exhibit the same severity of hypertension-related mortality as their “stroke belt” counterparts. This thus raises the question of whether race is the key concern or, more likely, whether regional attributes (e.g., dietary habits and exercise patterns) are more important.

Hispanic beneficiaries also suffer from significantly compromised health. Nearly one-half of all Hispanic Medicare beneficiaries perceive their health status to be fair or poor, as compared with only one-quarter of all whites.¹⁸ Hispanic persons reported worse health than white persons at every age. According to the U.S. Department of Health and Human Services, Hispanic elderly ages 65 to 74 years were 1.4 times more likely to be in fair or poor health than white elderly

five percent, respectively, for all races combined. In 1992, the five leading causes of cancer death in African Americans were as follows: 1) lung cancer; 2) colon-rectum cancer; 3) prostate cancer; 4) breast cancer; and 5) pancreatic cancer.

8American Cancer Society, Cancer Statistics For African Americans: 1996-1997. Department Of Epidemiology. (<http://cancer.org/statistics/96csaa/csaamort.html>)

9Center For Health Quality, Outcomes, & Economic Research: Quarterly 2, Spring 1999.

10UCLA Center For Health Policy Research and The Henry J. Kaiser Family Foundation, Racial And Ethnic Disparities In Access To Health Insurance And Health Care. October 1, 1999.

11Henry J. Kaiser Foundation, A Synthesis Of The Literature: Racial And Ethnic Differences In Access To Medical Care. October 1999.

12Geiger HJ. “Race And Health Care—An American Dilemma?” *New England Journal Of Medicine*, V335, N11 (Sept 12, 1996): 815-16.

13National Diabetes Fact Sheet, 1998

14American Diabetes Association (2000). Home Page . [Www.Ada.Org/](http://www.Ada.Org/) (Accessed, 2/28/00)

15Culture-Sensitive Health Care: African American. Diversity And Health Resource Center, Accessed 10/00. (<http://www.amedpub.com/health2k/health/indexaf.html> or <http://www.amedpub.com/health2k/index.html>)

16Pickle LW, Gillum RF. “Geographic Variation in Cardiovascular Disease Mortality in US Blacks and Whites.” *Journal of National Medical Association*, 91:10 (October 1999): 545-56.

17Howard G. “Why Do We Have a Stroke Belt in the Southeastern United states? A Review of Unlikely and Uninvestigated Potential Causes.” *American Journal of Medical Science*, 317:3 (March 1999): 160-7.

18 Kaiser Family Foundation, Medicare’s Role for Latinos. April 1999.

people of the same age.¹⁹ Likewise, Hispanic/Latino elders reported greater instrumental activities of daily living dependencies and cognitive disabilities.²⁰ According to data collected by the National Center for Health Statistics, Mexican Americans specifically have a higher rate of uncontrolled hypertension than do whites, and the Hispanic/Latino population as a whole has an elevated incidence of tuberculosis.²¹ According to a 1999 Barents Group report, diabetes among elderly Hispanic/Latino populations indicates that its prevalence is 100 percent greater than the non-Hispanic white population.²²

Financial Issues

For many of the members of the four subgroups, poverty remains one of the primary barriers to accessing needed health care services and, as a consequence, results in an increased susceptibility to illness. For example, twenty-six percent of African Americans age 65 or older live in poverty compared with only 8.2 percent of whites in that same age group.²³ African American elders tend to have significantly lower incomes than the general Medicare population. In 1997, the median income of African American seniors of \$11,628, compared to \$17,268 for elderly white Americans.²⁴

Members of the under 65 disabled cohort do not fare much better than their senior African American counterparts: fully 30% of under-65 disabled Medicare beneficiaries have incomes below 100% of poverty, and 33% are between 100% and 200% of poverty.²⁵ Moreover, they experience significant barriers to securing adequate coverage in the private insurance market; even when available, the range of services and long-term supports these individuals need are often not covered.²⁶ As a result, the disabled rely heavily on public programs, such as Medicare and Medicaid, to cover the costs of their health services, and are disproportionately represented in the public sector.

- ◆ 20% of the under-65 disabled, as compared to 36% of elderly beneficiaries, have employer coverage (generally through a spouse) that acts as primary payer;
- ◆ 36%, as compared to 11% of elderly beneficiaries, have Medicaid coverage;
- ◆ 8%, as compared to 28% of elderly beneficiaries, have Medigap (provisions in law permit Medigap insurers to deny coverage to under-65 disabled);

19Health, United States, 1999. Health And Aging Chartbook, U.S. Department Of Health And Human Services (<http://www.cdc.gov/nchs/data/hus99.pdf>).

20Carrasquillo O, Lantigua RA, Shea S. "Differences in functional status of Hispanic versus non-Hispanic White elders: data from the Medical Expenditure Panel Survey." *Journal of Aging Health*. 12:3 (Aug 2000): 342-61.

21Healthy People 2000 Review, 1995-96. National Center for Health Statistics. 1996. Hyattsville, MD: U.S. Public Health Service.

22 Barents Group, L.L.C. Summary Report On The Hispanic/Latino Medicare Population. April 14, 1999.

23Administration on Aging. The Many Faces of Aging: Resources to Effectively Serve Minority Older Persons. Facts and Figures: Statistics on Minority Aging in the U.S. <http://www.aoa.gov/minorityaccess.stat.html>. Retrieved Jan. 17, 2001.

24National Caucus and Center of Black Aged, Inc. A Profile of Elderly Black Americans, October 1998.

25Henry J. Kaiser Family Foundation, The Faces of Medicare: Medicare and Low-Income Beneficiaries. July 1999.

26National Academy of Social Insurance, The Environment of Disability Income Policy: Programs, People, History and Context, Interim Report of the Disability Policy Panel.

- ◆ 4%, as compared to 10% of elderly beneficiaries, are enrolled in a Medicare HMO; and
- ◆ 27%, as compared to 10% of elderly beneficiaries, have only traditional Medicare coverage.²⁷

Overall, disabled beneficiaries have more functional limits, are in poorer health, have lower incomes, and experience more barriers to care than elderly beneficiaries [cite – O’Brien Davis, “Profile of Persons with Disabilities in Medicare and Medicaid.” Health Care Financing Review. 17:4 (1996): 179.]

There is admittedly tremendous diversity among the Hispanic population in the United States, which includes recent migrant workers from Mexico and Central America, as well as Cuban immigrants who have been in this country for two or more generations. Yet, our TEP participants did not note any particular concerns about financial challenges faced by Hispanic Medicare beneficiaries. Nevertheless, a review of the data indicate that Hispanic Medicare beneficiaries (as a group) are significantly less likely than their white counterparts to carry supplemental insurance policies. While 29 percent of white Medicare beneficiaries hold Medigap policies, only 10 percent of Hispanic beneficiaries have comparable coverage. More frequently, in fact, elderly Hispanics will rely upon Medicaid to supplement Medicare; more than 25 percent of Hispanics receive some level of Medicaid assistance to supplement Medicare, as compared with 11 percent of whites.²⁸ Thus, there appears to be a significant number of Hispanic Medicare beneficiaries whose access to care may be compromised because of insufficient supplemental health coverage.

Finally, there was little discussion among the TEP members or even within the literature about the financial issues facing seniors in self-described fair or poor health. While fiscal issues may not have emerged through these two methodologies as the most salient dimensions for this cohort of persons, we shall see that among Medicare M+C enrollees money does matter greatly. This issue is discussed in more detail below, in the section that covers findings from the focus groups. Regardless which of the four subgroups was being discussed, the literature and TEP participants suggested three steps that Medicare managed care plans could take to ease the financial burden on M+C enrollees. These steps included finding ways to reduce the cost of prescription drugs for beneficiaries, as well as limiting other out-of-pocket expenses, such as deductibles or non-covered services. In addition, there was a near-unanimous suggestion for M+C plans to provide transportation for beneficiaries so that they could get to and from medical appointments. In some cases, the service is needed because beneficiaries are too frail to drive or their disability impedes their ability to operate a vehicle; just as often, though, beneficiaries simply cannot afford to own and maintain a motor vehicle. If they are constantly faced with meeting the cost of public transportation, many financially strapped beneficiaries may opt to forego a medical visit altogether.

Cultural Issues, Cultural Competence

When we focused specifically on the two subgroups classified as “vulnerable” (i.e., African Americans and Hispanics) issues of cultural difference readily emerged in both the literature

²⁷Henry J. Kaiser Family Foundation, *The Faces of Medicare: Medicare and the Under-65 Disabled*. July 1999.

²⁸Kaiser Family Foundation, *Medicare’s Role for Latinos*. April 1999.

reviews and in the TEP discussions. For both groups, there were concerns about the extent to which group members' cultural beliefs might affect communication with a care provider and subsequent access to services. For Hispanic beneficiaries, specific cultural factors that need to be considered by providers include:

- ◆ Beliefs and/or reliance on non-Western remedies and non-traditional healers;²⁹
- ◆ Perceptions Hispanic/Latino patients may have regarding the patient/physician relationship;³⁰
- ◆ Strong religious conventions or beliefs;³¹
- ◆ Variations in the structure of the family unit.³²

Any combination of these cultural differences may hamper effective dialogue between the provider and the patient, and thus limit the degree to which a provider may render appropriate and timely health care service. Hispanic/Latino patients may rely on treatment advice from alternate providers (e.g., *curanderos*, *yerberos*, or *santeros*) and/or non-western remedies to alleviate symptoms.³³ In addition, many Hispanics opt to self-treat rather than seek medical care, yet use medications that are available over-the-counter in Latin American but that are prescription-only or banned in the United States. Consequently, treatment regimens prescribed by traditional providers and non-traditional providers may lead to adverse drug interactions, and subsequently pose serious medical complications for the patient. As a result, traditional probes into existing medications during medical history-taking sessions need to account for the possibility of self-medication that is culturally driven, in order to avoid unnecessary and/or dangerous treatments. Health care providers treating Hispanic/Latino patients also need to probe to uncover any existing clinical symptoms that are not perceived as "medical concerns" by the patients themselves.

It should also be noted that reliance on extended family members for support tends to be more pronounced in Hispanic/Latino families. According to reports by Barents Group³⁴ and the Intranet Diversity and the Health Care Resource Center,³⁵ a greater proportion of Hispanic/Latino seniors live with their grown children or with other relatives than live alone or with a spouse. As a health care provider or a health plan customer representative, sensitivity to a Hispanic senior's caregiver is important to ensure cooperation from all parties. Additionally, a greater deference tends to be paid to elders by younger members of extended families within the Hispanic/Latino community.³⁶ More specifically, younger adults may defer from providing their

29Cultural-Sensitive Health Care: Hispanic. Diversity And Health Care Resource Center, <http://www.amedpub.com/vmain.html> (Accessed: 10/00).

30Henry J. Kaiser Family Foundation, *Race, Ethnicity & Medical Care, A Survey Of Public Perceptions And Experiences*, 1999.

31Cultural-Sensitive Health Care: Hispanic. Diversity And Health Care Resource Center, <http://www.amedpub.com/vmain.html> (Accessed: 10/00).

32Cultural-Sensitive Health Care: Hispanic. Diversity And Health Care Resource Center, <http://www.amedpub.com/vmain.html> (Accessed: 10/00).

33Cultural-Sensitive Health Care: Hispanic. Diversity And Health Care Resource Center, <http://www.amedpub.com/vmain.html> (Accessed: 10/00).

34Barents Group, L.L.C. *Summary Report On The Hispanic/Latino Medicare Population*. April 14, 1999.

35 Intranet Diversity And Health Care Resource Center. <http://www.amedpub.com/vmain.html> (Accessed: 2/1/00)

36Cultural-Sensitive Health Care: Hispanic. Diversity And Health Care Resource Center, <http://www.amedpub.com/vmain.html> (Accessed: 10/00).

opinion if their advice conflicts with a more senior family member. Provider awareness of this conflict may facilitate the bridging of a cultural gap and encourage questions concerning the health and well-being of Hispanic seniors under the care of the extended family.

Perhaps the most prevalent barrier encountered in the health care system by the Hispanic/Latino population involves language differences and communication difficulties³⁷. According to the 1997 data collected by the U.S. Census Bureau, approximately 44 percent of the Hispanic/Latino population was foreign-born.³⁸ For a significant portion of this group, Spanish is the first language. Due to a lack of Hispanic/Latino providers, many of these patients may encounter communication barriers with their health care providers. Although many non-Hispanic providers may speak Spanish as a second language, they are less likely to be able to converse in Spanish to a degree that would facilitate the comprehensive exchange of medical information.³⁹ Often, Hispanic/Latino patients report that providers fail to listen to them, fail to consistently ask about other treatment regimens being used, and leave the encounter without being assured family members could get needed care.

Less frequently acknowledged in the literature is the extent to which health care beliefs in the African American community affect these individuals' access to necessary services. One exception to this is the work of several researchers who have studied the effect of African-American attitudes and beliefs regarding cancer. Beliefs regarding cancer and identified in the research include the following: personal immunity from the disease; providers are powerless against cancer; health status is dictated by fate; and physicians cannot be trusted.⁴⁰ Analysis of data collected from a survey administered at two African-American churches in different parts of the country found that 30 percent of the respondents indicated that their health was dependent on fate or destiny.⁴¹ These results were corroborated by another study that revealed that African-American women - regardless of their level of educational attainment - were significantly more likely than white women to believe in chance, or depend on powerful other factors for their health.⁴² Other studies have shown that cultural beliefs discourage minority women from seeking care and are likely to play an important role in the stage at which breast cancer is diagnosed.^{43,44}

³⁷ It is important to recognize, however, that there is tremendous variation in the "Hispanic population" across the United States, both in terms of fluency in English as well as in cultural beliefs. Mexican Americans in the southwestern U.S., for example, may have had family in this country for several generations, and may be fluent speakers of Spanish, English, and "Spanglish." Elderly Cuban Americans in Florida, however, may have migrated to this country more recently, and may not have been acculturated to the same degree as their southwestern counterparts. These and other differences should be kept in mind when discussing Spanish-speaking peoples' encounters with the health care system in the United States.

³⁸Reed J, Ramirez RR. "The Hispanic Population In The United States: March 1997 Update." *Journal of the American Medical Association*, 2:265 (January 9, 1991): 238 (4).

³⁹Reed J, Ramirez RR. "The Hispanic Population In The United States: March 1997 Update." *Journal of the American Medical Association*, 2:265 (January 9, 1991): 238 (4).

⁴⁰CMS Market Research For Beneficiaries: Second Inventory Report. Barents Group; August 15, 1997.

⁴¹Lewis RK, Green BL. "Assessing the health attitudes, beliefs, and behaviors of African Americans attending church: a comparison from two communities." *Journal of Community Health*, 25:3 (June 2000): 211-24.

⁴²Barroso J, McMillan S, Casey L, et al. "Comparison between African-American and white women in their beliefs about breast cancer and their health locus of control." *Cancer Nursing*

⁴³Hunter CP, Redmond CK, Chen VS, et al. "Breast Cancer: factors associated with stage at diagnosis in black and white women. Black/white cancer survival study group." *Journal of National Cancer Institute*, 85 (1993): 1129-1137.

Research on both Hispanics and African Americans also has revealed that members of both groups evince a general distrust of the medical system, although the source of that distrust varies by ethnic group. For African Americans, the source of this distrust is well founded and based upon centuries of racial discrimination and maltreatment.⁴⁵ In addition to the culturally devastating effects of being forced to live in a country which officially sanctioned slavery for over two hundred years, and the subsequent decades-long struggle for equality and civil rights, African Americans have been subject to other abuses at the hands of the federal government. The most commonly known incident is the forty-year long Tuskegee Syphilis Experiment, which was made known to the public in 1972.⁴⁶ The Tuskegee study created for African Americans a tremendous sense of betrayal by the federal government's "medical misconduct."⁴⁷ Moreover, the fact that so many researchers were involved in this unethical experiment and yet only one person stood out as a "whistle-blower", has undoubtedly increased the level of fear and distrust of both the Federal government and the medical establishment in general among African Americans. As a result, African-American individuals may yet be apprehensive about seeking care from government-sponsored providers or programs.

According to a 1999 study by Ross, many cultures, including segments of the Hispanic/Latino community, have a natural distrust of governmental entities.⁴⁸ This may have significant implications for health plans that have Medicare and Medicaid contracts. Obtaining compliance from Hispanic/Latino enrollees with respect to health plan protocols, especially from those who might be eligible to receive benefits through both Medicare and Medicaid, may be difficult if such enrollees resist what they perceive to be government intervention. Although eligible for certain government programs, some segments of the Hispanic/Latino population may not seek out services or assistance as a result of incorrectly fearing deportation. In addition to exacerbating illnesses, serious health risks may be posed to family and community members, particularly in cases of communicable diseases (e.g., tuberculosis).⁴⁹

The theme of cultural competence was clearly raised in the literature and by the members of both the African American and Hispanic TEPs. Yet, careful examination reveals that all of the literature summaries and all four TEP groups made a *de jure* call for "cultural competence" with respect to *each of the four subgroups*. When "culture" is broadly defined as a shared set of beliefs, values, behaviors that is learned as part of growing up in any particular social environment, then each of our four subgroups has clear, cultural features that should be taken

44Lannin DR., Mathews HF, Mitchell J, Swanson MS, Swanson FH, Edwards MS. "Influence of Socioeconomic and Cultural Factors on Racial Differences in Late-Stage Presentation of Breast Cancer." Journal of the American Medical Association, 1998; 27: 1801-1807.

45Gamble VN. "Under the shadow of Tuskegee: African American and health care." American Journal of Public Health, 87(November 1997): 1773-78.

46Mullan, F. "Plagues and Politics---The Story of the United States Public Health Service," Basic Books, Inc., 1989.

47America's Dirty Little Secret. Bad Blood: The Tuskegee Syphilis Experiment. <http://www.aabhs.org/tisk.htm> (accessed 12/29/00)

48Ross H. "Minorities Less Likely To Have Employer-Sponsored Health Insurance." Closing The Gap Newsletter. U.S. Department Of Public Health, Office Of Public Health, August/September 1999, P4. (www.omhrc.gov/ctg/ctg.Accnew.pdf).

49Cultural-Sensitive Health Care: Hispanic. Diversity And Health Care Resource Center, <http://www.amedpub.com/vmain.html> (Accessed: 10/00).

into consideration if these individuals are to be provided with optimum care. The call for physicians with training in gerontology, for example, recognizes (if tacitly) that culture changes over time, and that elderly Americans – many of whom grew up during the Depression - were raised with a unique set of beliefs, values, and health behaviors. In addition, seniors are impacted by our wider cultural beliefs around the aging process, effects that gerontologists could recognize and readily incorporate into their treatment planning processes.

Thus, “cultural competence” can be defined broadly as a set of behaviors, attitudes, and policies that enable a system, agency, or group of professionals to work effectively in cross-cultural situations.⁵⁰ Cross et. al. stated that “a culturally competent system of care acknowledges and incorporates, at all levels, the importance of culture, the assessment of cross-cultural relations, vigilance towards the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to culturally unique needs.” Those needs can include ethnically driven issues, as well as issues related to age cohort, disability status, type of disability, among many other characteristics. Based on these findings, an effective system of care will consist of providers and payors who are cognizant of and responsive to the unique needs of their various plan members.

Organizing Framework for Managed Care Plans

Despite a comprehensive site visit protocol that focused on issues of cultural competency in health care plans, our site visit team members found that health plans generally do not segment or stratify their membership based on race or ethnicity. Some plan representatives expressed the belief that such profiling was illegal, and noted that their plan simply did not keep this demographic information lest it leave them open to lawsuits. While three plans noted a general indication of racial/ethnic distribution of plan members by correlating zip codes of their members with census tracking data, only one plan we visited had mapped its membership according to race/ethnicity.⁵¹ Of those plans that reported having programs geared specifically for vulnerable minorities, most of them focused on the needs and barriers facing Hispanics/Latinos, primarily issues related to language and communication. Programs and policies specifically designed for African Americans were largely non-existent among the sites we visited.

The lack of a Federal mandate requiring Medicare plans to track the race or ethnicity of their enrollees may well be the reason plans do not keep this information. Because health status is the dimension along which the insurer has assumed financial risk, and because there is no Federal requirement that racial or ethnic data be collected, plans appear to be interested in screening enrollees for chronic and disabling health conditions, *not* ethnic identity. To be sure, there is a well-documented correlation between race/ethnicity and the prevalence of certain chronic and disabling conditions. However, when a plan stratifies its membership, it does so based on

⁵⁰Cross T, Bazron BJ, Dennis KW, Isaacs MR. Towards a culturally competent system of care. Vol. I: Monograph on effective services for minority children who are severely emotionally disturbed. Washington: Georgetown University Child Development Center, CASSP Technical Assistance Center; 1989.

⁵¹This plan was a cost-based HMO run by a county government. As a result, the plan had direct access to the county health department’s records and was able to correlate its membership with the health department’s data tracking systems to generate not only a virtual map of the plan’s membership, but also a distribution of health problems within the county (e.g., infectious disease outbreaks).

complex medical needs that are associated with high costs and/or frequent use of medical services. Thus, common mechanisms that health plans use to manage these conditions include case management, disease-specific management, and the use of “senior ambassadors,” or advocates, which we discuss below.

Case management

Case management is a common strategy that can be used to deliver care to individuals in fair or poor health. According to the Case Management Society of America, it is a collaborative process that includes the following components: case selection, problem identification, planning, coordinating, monitoring, and evaluation.⁵² The HMO Workgroup on Care Management notes that effective case management programs manage unstable situations before crises occur and mobilize resources to address them.⁵³

There are two primary types of case management. Low-intensity/high-volume case management is a system in which a few case managers coordinate services for a large number of individuals with very little person-to-person contact. High-intensity/low volume case management exists when each case manager works directly with a small number of patients for a given episode of care or over time. This type of case management is less common than the other, but more appropriate for older patients in fair or poor health.⁵⁴

For those elderly in fair or poor health, case management is essential in bridging services and other levels of care and in creating a seamless continuum of care that helps achieve an integrated delivery system. According to the work of Cheryl Phillips-Harris, MD, the components of an integrated case management program should include: a process that links information about patients between providers and levels of care; service flexibility that allows for care to be delivered based on patient needs and availability of resources; an interdisciplinary focus on patient needs (clinical, social, spiritual, and environmental); and longitudinal care coordination that is not event-specific.⁵⁵ Boulton has also found that the effectiveness of case management often depends on its integration into primary care. Ideally, the primary care physician and case manager should work in the same setting, facilitating effective communications about high-risk seniors’ plans of care.⁵⁶

A study conducted by the University of Minnesota identified and examined innovative systems of care for older people with chronic conditions.⁵⁷ The most common types of programs identified in the study were case management programs. All of the surveyed case management

⁵²Case Management Society of America. Standards of Practice for Case Management. Little Rock, AR, 1995.

⁵³AAHP Foundation, Geriatric Case Management: Challenges and Potential Solutions in Managed Care Organizations. HMO Workgroup on Care Management, Washington, D.C. January 1999.

⁵⁴Phillips-Harris, C. “Case Management: High-Intensity Care for Frail Patients with Complex Needs.” Geriatrics, February 1998.

⁵⁵Phillips-Harris, C. “Case Management: High-Intensity Care for Frail Patients with Complex Needs.” Geriatrics, February 1998.

⁵⁶Boulton C, Pualwan T, Fox P, Pacala T. “Identification and Assessment of High-Risk Seniors,” The American Journal of Managed Care, 4 (1998): 1137-1146.

⁵⁷Boulton C, Kane R, Pacal J, Wagner E. “Innovative Healthcare for Chronically Ill Older Persons: Results of a National Survey.” The American Journal of Managed Care, September 1999.

programs are designed to improve the coordination of health-related services and to decrease the total costs of care. Most programs target at-risk patients, assess their clinical status, develop care plans, coordinate their health-related services across several sites, and monitor their progress. Many of the programs use a screening instrument to target the recipients of case management; some also rely on referrals from providers and on self-referrals. Other innovations in case management included: providing geriatric nurse practitioner or geriatrician backup for case managers who are social workers; using electronic media to share clinical data among case managers, physicians, nurses, and admissions personnel; and sharing resources and responsibilities for care between health care systems and community service agencies.

Finally, the HMO Workgroup on Care Management reported in its 1999 report entitled, *Geriatric Case Management: Challenges and Potential Solutions in Managed Care Organizations*, that case management successfully reduced hospital use and increased client satisfaction. The following features were identified as common to successful programs:⁵⁸

- ◆ Careful targeting of older adults in fair or poor health, or of specific conditions;
- ◆ Case managers who are specifically trained and skilled in assessment and care of older adults;
- ◆ Formal written care planning with involvement of the primary care physician and family;
- ◆ Case management that spans various sites of care, and
- ◆ A sophisticated information system for monitoring clients' status across sites of care.

Disease management

Disease management is a proactive way to deliver health care to chronically ill individuals that includes strategies such as integrating care across the continuum, enhancing the traditional physician paradigm with efforts to reduce the frequency or severity of exacerbations of chronic illnesses, and employing non-physician practitioners who specialize in the target disease. Diseases targeted by such programs are those in which the available strategies may alter the natural course of the illness, such as congestive heart failure, asthma, chronic obstructive lung disease, and diabetes.⁵⁹ Common conditions often associated with chronic illness also can be effectively managed through disease management, such as chronic pain. While most MCOs do not have a formal program in place to manage pain, there are a few exceptions.⁶⁰ Clinics have been designed to focus solely on the treatment of pain commonly experienced by older people, such as that associated with arthritis, compression fractures from osteoporosis, and chronic shingles.⁶¹

Dementia is another disorder that meets most of the criteria that make it eligible for management via a structured disease management program. Not only do we see increased levels of cognitive

⁵⁸HMO Workgroup on Care Management, 1999.

⁵⁹Fillit H, Knopman D, Cummings J, Appel F. "Opportunities for Improving Managed Care for Individuals with Dementia: Part 2—A Framework for Care," *The American Journal of Managed Care*, 5 (1999): 317-324.

⁶⁰Edlin M. "Putting together painless DM approaches for patients," *Managed Healthcare*, September 1999.

⁶¹Edlin, *ibid*.

disability in the under 65 disabled cohort, but also, as age increases, the incidence of cognitive impairment increases. Over 10 percent of the population aged 65 and over suffers from Alzheimer's disease and almost 50 percent of people over the age of 85 is affected by Alzheimer's disease or some type of dementia.⁶² Since dementia is a chronic, progressive disorder that requires a comprehensive multidisciplinary approach, managed care potentially offers an effective way to care for patients with dementia.⁶³ In general, management of dementia focuses on maintaining or improving functional health and quality of life for affected individuals and their caregivers, reducing unnecessary physician and hospital visits, and delaying nursing home placement.

Mechanisms for Outreach, Engagement, and Conflict Resolution

Several of the plans that we visited recognized that in addition to the attentions of a case manager, many enrollees need additional supports to access both preventive as well as palliative services. Plans thus put into place various programs – including peer supports, as well as an ombudsman program – to ensure that their members get the care that they need. One plan, for example, developed a member advisory committee called the “Senior Ambassadors.” Plan members who comprise this committee are looked upon for commentary regarding the M+C plan's performance, as well as additional member needs and concerns. The Ambassadors also represent the plan during health fairs or gatherings, and assist with answering any questions that potential enrollees might have. Another plan visited by our research team attributed its ongoing success with its membership to the plan's interactions with community-based organizations, its partnerships with advocates of social services, and its involvement with various faith-based organizations. Partnerships with various community organizations led to the development of a “Navigators” program, which used bilingual individuals to conduct special outreach efforts on behalf of the plan (e.g., primary prevention education around flu vaccines), as well as to provide interpretation services for individual medical appointments, if necessary.

Finally, one plan had multiple mechanisms in place to ensure that enrollees received the services that they needed, and that questions were answered or conflicts resolved in a timely fashion. To help improve the appropriate use of medical services, the plan installed “white courtesy phones” in the plan-owned clinics and some of the participating hospitals. If a member had a question regarding coverage, the providers had been instructed to refer to members to the telephones so that they could receive authorization prior to undergoing specific treatments. The plan believed that this helped to ensure that the members were using the right facilities for the right types of medical conditions. In the event that a member could not resolve an issue, however, the member would be referred to an ombudsperson. The ombudsperson is an independent arbitrator who represents the member and tries to find a resolution to the individual's complaint. In this particular instance, the ombudsperson reported directly to the county's public health director.

In summary, findings from our visits to eleven different M+C plan sites indicated that the plans segment their enrollee population on the basis of health status, and not ethnic identity. While this finding may seem disappointing to those patient advocates who wish to see a more culturally

62Della Penna R, Rosenthal M. “Dementia Management, Medicare Managed Care Partnership: Kaiser Permanente and the Alzheimer's Association,” *Drug Benefit Trends*, March 1998.

63 Fillit, op cit.

competent health care system, the results should not be at all surprising when one considers the context in which these plans operate. Specifically, the plans – many of which operate as for-profit entities – function primarily as insurers. While appropriate provision of quality care informs insurer decisions, these are financial institutions for whom managing financial risk is an essential analytic dimension. As a consequence, the salient dimension of their enrollee population is the extent to which enrollees' health conditions impact the plans' overall financial profile. While case management, disease management, and even peer support programs may ultimately benefit the enrollees, the intent of these approaches is to help the plans to maximize quality and conserve resources for proven-effective procedures, necessary hospital admissions and tests, and the like.

Beneficiaries' Worldview

The findings from the literature reviews and the TEP discussions suggest that M+C enrollees can be divided into (at least) four subgroups, each of which has unique needs and requirements of its health plan. The results of the site visits to M+C plans countered this perspective, suggesting that the health plans do not classify their members by our subgroup characteristics, but rather by the extent to which the beneficiaries' health statuses may consume the plan's finite resources. Our main analytic challenge in interpreting the findings from the focus groups was to determine which categories (or combination of categories) – ethnicity, age, or health/disability status – were perceived by beneficiaries to be negatively affecting their access to health services. The team approached this project fully cognizant that ethnic minorities have an overall lower health status in this country, and anticipated that our findings would reveal some perceived correlation between ethnicity and access to adequate health care services. Similarly, we envisioned that a majority of our seniors would attribute difficulties with accessing services to their age, either due to outright discrimination or challenges to mobility. After careful review of the group narratives, however, only one of the three assumed dimensions – health status – emerged as salient to beneficiaries' experiences. Participants did not describe their barriers to care as deriving from their ethnic identity or their age, either alone or in concert with any of the other barriers that emerged from discussions. In fact, in two of the African American groups, concern was expressed about the uniform composition of the group participants. One respondent said that while he understood the importance of dividing the groups by ethnicity or race, he added, "It's just that if a Hispanic was sitting here instead of me, you could still get that input."

In point of fact, participants consistently indicated that their health needs and their barriers to service are neither predetermined nor limited. Instead, there are a number of factors that can combine in different ways and under unique and varying circumstances to create difficulties for them to get the care that they need, as depicted in the logic model below:

First, does the beneficiary have any exceptional health care needs? If not, then the managed care plan and its benefits structure are virtually non-issues. For those beneficiaries who do have significant health problems, though, a major concern is whether or not the benefits package covers the needed treatment(s). When those services are covered by the plan, then the respondents seem relatively pleased with their M+C plans. When those needed services are not covered, however, the individual's satisfaction with the HMO varies with the degree to which s/he is able to work around the barriers to service. Those individuals who are able to negotiate

the roadblocks – either by themselves or with the assistance of another person (e.g., family member, physician) – seemed annoyed at having to go through such machinations, but were generally able to get the care they needed while enrolled in a Medicare managed care plan. Those individuals who lacked the ability or support to negotiate the barriers, however, emerged as the Medicare managed care beneficiaries who were experiencing the greatest distress and, in most cases, the greatest dissatisfaction with their plans. The case studies below offer examples of the impact of this hierarchy of categories on beneficiaries’ experiences.

Beneficiaries Without Serious Health Care Needs

One of the assumptions behind the study design was that beneficiaries over the age of 65 who described their health status as “good” or “excellent” would require fewer health care services, and thus might have a different perspective on their managed care plans, than their more medically involved counterparts. Indeed, the focus group participants who indicated that they were relatively healthy offered minor difficulties with the ways in which their plans functioned, such as long periods on “hold” when trying to get updated plan information via telephone, or small increases in co-payments for office visits or medications. Consistent with our working assumption, however, these difficulties were described mostly as “annoyances” because of the relatively good health status of the respondents. An increased co-payment for an office visit is but a paper- or even one-time irritation if an individual rarely visits a physician. Similarly, bearing a higher proportion of the cost of medications is a burden only if one actually needs significant amounts of medication for a health condition. Indeed, many of our healthy participants noted that they were “satisfied” with their Medicare managed care plans, but added that because they had been relatively healthy so far, there was very little on which they could offer comments.

Their present state of good health notwithstanding, however, many of the participants expressed concern about developing serious medical conditions in the future, and wondered if their current plan would adequately meet their care needs. One woman in Alabama, for example, had worked all of her life and had what she believed to be excellent insurance coverage up until she retired. The aging process, combined with the switch to uncertain coverage under a Medicare managed care plan, left her concerned about the possible financial impact of a serious illness:

“The older I get I’m getting kind of uneasy...I didn’t have any problems until after I got to [age] 65, [before which] I was paying \$100-and-some-dollars [for insurance] and it was no problem. The minute I got 65 and I wanted to use my insurance that I already had plus Medicare to eliminate my payments...From my understanding you go into bankruptcy if something really, really happened to you...I think there should have been a fee or small amount of money that you paid so that the two could take care of your expenses. And I think I would rather have an insurance that keeps me from paying anything if I have something go seriously wrong. It just so happens that I’ve been somewhat healthy but now it’s scary, because I have only one son and he has his children and I don’t wish to be any expense on them. ...I’m getting scared the older I get.”

In summary, respondents in relatively good health described few problems with their Medicare managed care plans, in large measure because they heretofore had had little need to interface with the plan or their benefits package. Yet, there was widespread concern that a sudden change

in health status might financially devastate an individual and/or his/her family. Managed care did little to ease those concerns, as several of the stories below attest.

Beneficiaries with Serious Health Care Needs...

The vast majority of beneficiaries with whom we spoke comprised either the under 65/disabled cohort, or seniors who reported to be in “fair” or “poor” health. These individuals presented with a wide array of devastating health conditions, including diabetes, high blood pressure, heart disease, cancer, brain injuries, AIDS, asthma, emphysema, and various combinations of illnesses. Particularly startling were those Medicare beneficiaries under 65 years of age, whose conditions – including kidney failure, mental illness, and physical disabilities resulting from accidents – had so devastated them that they were no longer able to work.

Despite the severity of these individuals’ health conditions, there was not uniform agreement as to whether managed care “in general” was a good or a bad thing. Even within groups of enrollees from the same plan, satisfaction depended upon the combined effect of several dimensions, including the intensity of individual’s medical condition and the degree to which the plan benefits package covered the individual’s specific care needs. As importantly, where the plan failed to cover a treatment, satisfaction seemed to vary with the extent to which the individual was able to find an alternative way to get his/her medical care needs met.

...And the Benefits Package Covers Needed Treatments

At all four locations in which we conducted beneficiary focus groups, we encountered individuals who had very involved medical conditions, but who reported satisfaction with their plans because the plan had covered the cost of their treatments. Such treatments included everything from open-heart surgery and inpatient hospital care, to a mastectomy and chemotherapy for breast cancer. While in many cases the medical conditions were presenting challenges to the individuals’ quality of life, the managed care plans were not proving to be an additional burden with which these beneficiaries had to deal. The following narrative is from a medically involved beneficiary who had dropped out of one Medicare managed care plan in favor of a second, only to discover that the second was not going to cover his medical costs. His story clearly illustrates the financial importance of reliable health care coverage, and its impact on his subsequent enrollment decisions:

“My name is John. I’ve been on [HMO A] since ’96. I was on [HMO A] before, but then I switched over to [HMO B], I don’t know why. I’m a severe diabetic and there were a lot of complications. I’m a chronic anemic. I have cirrhosis of the liver and also I have renal failure and just everything. ...I was taking three shots at one time for the chronic anemia. [And] they also found lymphoma cancer. They caught it in time. I went through the whole process, the chemo and everything, and everything’s fine. ...[But] because of the, all the [treatments] I had to go through [while on HMO B] my bills really accumulated in the thousands, and so I’m left with a bill that now I have to pay for the rest of my life. Now, I switched back to [HMO A]. And as far as those shots I’ve been taking, I’ve reduced them from three times a week, which I understand that every shot is very close to \$800 a shot. I have to say that I don’t have anything against [HMO A] because they are paying my bills now.

“There are a lot of factors that everybody [else in the focus group] has mentioned ...a lot of times I stop and think maybe I should switch [to another HMO] because of the referrals, because of the payments going up on the medications... [But] it’s too much for me. I’m on a fixed income. I just lost my wife in November to liver cancer. So it’s just left my income, plus what my daughter and my son can [offer].... That’s not enough to run a household, plus see doctors, plus help my daughter with what she needs, too. ...I have to keep with [HMO A] because I can’t afford to switch right now. It would be a big mess for me. ...I just saw a doctor yesterday and he upped my shots from one to two shots a week again. They had reduced them, but now they’re back up again. My liver count and everything else is showing up ...and of course I need those shots ...and I have to take those for the rest of my life.”

Thus, this gentleman recognized the same issues with his HMO that others in his cohort were concerned about, including trouble getting referrals and a rising prescription co-payment. However, those particular matters are more “hassles” when viewed against the backdrop of accumulated medical bills that will take the remainder of his life to pay off. It is important to recognize that how beneficiaries rank the plans’ performance is not an absolute, but rather based on their specific array of treatment needs and the extent to which the plan meets the cost of those treatments.

...And There is No Coverage, but Many Creative Alternatives

Even more common than the type of case cited above were those instances in which beneficiaries’ medical needs were **not** being covered by their Medicare managed care plans. The needs were many and varied, and ranged from difficulty getting referrals to not having coverage for brand-name medications. To a person, there was frustration and general dissatisfaction with plans where coverage was either problematic or denied altogether. In many instances, however, beneficiaries had found ways to work around the roadblocks established by the plan in an effort to get the treatments that they needed. Sometimes, for example, beneficiaries simply shrugged their shoulders and paid for the treatment out-of-pocket. Mostly these were relatively low-cost interventions, such as seeing a long-time physician who was not covered by the plan, or paying for a brand-name medication because it seemed to work more effectively than the plan-covered generic version.

One of the unanticipated findings from the enrollee focus groups, however, was the extent to which the M+C enrollees as a group were facing enormous and quite serious financial challenges. Indeed, we learned that many Medicare beneficiaries had opted to enroll in M+C plans because of financial reasons. Several participants noted that they had enrolled in a managed care plan because they could no longer pay the thousands of dollars per year (\$7000, in one case) in premiums for health insurance coverage:

“During all the years when my husband and I were divorced, I signed up for Blue Cross / Blue Shield individual plan. I carried that and year after year, they were just upping their rates and upping their rates and upping their rates. And I guess...by the time I was sixty-two, the plan was costing me...I paid it quarterly, [but] even if I paid it monthly it’d still average out the same, but it was \$378 a quarter. Which was an average of \$126 a month plus what they were taking out of

my disability check. So I was paying like \$178 a month for health care insurance. I had no coverage for medications through Blue Cross Blue Shield, so my medicine I had to buy straight out. And my disability check, because in beauty work twenty years ago, it wasn't as good as it is...beauticians work wasn't paying as much as they're paying [now]. So therefore my disability check wasn't amounting to very much. I am just now reaching the \$500 mark for monthly income."

Other beneficiaries had been enrolled in traditional Medicare, but the 80/20 cost-sharing and lack of prescription drug coverage held the potential for disaster, they said, since their incomes were now fixed. There was little question that certain of the Medicare managed care plan benefits – in particular, prescription drug coverage – were intrinsically appealing. Nevertheless, the vast majority of focus group participants indicated that they had enrolled in Medicare managed care because the premiums were affordable, and because they could reasonably estimate their financial responsibility should they require intensive medical care.

Because of these widespread financial challenges, not all beneficiaries were able to shoulder the costs of getting treatment outside of what the plan would pay for, and thus had to seek other ways of getting their medical care. Oftentimes, beneficiaries found an ally in their primary care physician, who would provide them with samples of a badly-needed-but-expensive prescription drug. This was especially true, it seemed, for some of the newer, high-cost antibiotics, which were not always covered by a managed care plan and whose costs were beyond the reach of the enrollees. Some beneficiaries reported having to explicitly request such samples from their doctors, although others – who perhaps had a longer-standing relationship with their physicians – were simply given the medications without having to reveal their financial concerns.

Beneficiaries who were veterans of the armed forces often reported using the Veterans' Administration facilities to get their medical care. Once again, this was most commonly reported as a means of obtaining prescription drugs whose costs were not covered by the individual's managed care plan. Veterans reported that for the cost of an annual physical (at \$50) and a \$5-per-prescription co-payment, they could get all of the prescription drugs through the VA and therefore simply ignored the barriers erected by their managed care plans. Less commonly, veterans reported using VA hospitals to get other medical treatments that they needed, but that their plans would not cover.

Far too frequently, beneficiaries had to resort to extreme measures to ensure that they got the medical care that they required. In locations where there was a county ("charity") hospital, many beneficiaries reported using this facility to compensate for a penurious managed care plan. This was regarded as a humbling – in fact, humiliating – last resort for many of our interviewees, whose medical needs had finally overridden their pride. Other beneficiaries resorted to even more drastic measures, in the hope that they could get some relief for their medical condition(s), as the following two examples illustrate.

"...I don't know what happened."

One of our focus group participants was an affable woman in her forties who originally hailed from Italy and who still spoke with a strong accent, despite being in America for many years. As

she entered the meeting room, both moderators were overwhelmed by the heavy, puffy, almost swollen appearance of this woman's body. When she began to describe her situation, she spoke of constant terrible pain in her joints, and a consequent inability to walk. "I'm in pain all the time. Me, pain. I've got a lot of pain in my legs. I don't walk a lot." The moderators asked if she does anything to distract herself from the pain, and she replied that she watches television and tries to read a little bit. "I used to have friends," she added, "but I don't have any more." Did they move? "No, no they don't move. It's because it's me. It's because I got too fat. I can't walk." With that comment, she burst into tears, and then shared her story:

"Every month I go to the doctor, and he runs lab tests for everything. So...look at me. I'm swollen. I look fat, but I'm not fat, I'm just swollen. I was on a diet and I lost 10 pounds. After 4 days I got it back again. And still I'm on a diet. I got no starch, no pasta, no grease, no oil, no milk, no cheese. Turkey breast, a little bit of salad... a little piece of meat like this....And my doctor said to me, 'I need to put you in the hospital. We have to keep you with no food. At all. At least 3-4 days to run this kind of test.' And he said to me, 'I'm going to call the insurance.' He then tells me, 'Forget about it, they don't want it. They're not gonna pay the hospital.' I said, 'They're not gonna pay?' 'No.' My doctor told them, he said, 'Every month she comes here, and I run all kinds of tests – blood, and blood, and blood.' They're paying for it – they pay! But if I go in the hospital, they're not going to pay. Because three days is \$9000, you know. So my doctor said, 'I'm not going to put you in the hospital.'

Despite her frustration, chronic pain, and what appeared to be a deep depression, this beneficiary concluded that in order to find out what was causing her difficulties, she would have to abandon the American medical system altogether. Because she still has family in Italy, and because they have socialized hospital care in that country, she called her family's doctor and arranged to go back to Europe to have the previously recommended in-hospital diagnostic test. Although her physician reportedly was quite willing to assist her with getting the necessary tests, she noted that he seemed baffled by the fact that she couldn't get the same test run over here: "But you are in America! It's so big, so many things. What happened?" he asked. Our beneficiary shrugged after relaying this quote, and noted quietly "I don't know what happened."

"...I have to charge it"

Many beneficiaries had enrolled in Medicare managed care plans because these plans offered prescription drug benefits not available under traditional Medicare coverage. The plans varied tremendously in terms of the dollar-amount for medication they would cover, from a low of \$200 per year in Alabama, to a recent increase in Miami to \$2400 per year. Invariably, however, we encountered enrollees who had hit the allowed limit and who then had to find other ways to obtain their medications. One woman described her experience as follows:

"...I got a letter about November and [the medication limit] was going up to \$1200. Last year, with my eye drops and my blood pressure pills and my potassium pills and my thyroid pills and my water pills plus eye drops – by May...When the pharmacy told me what I owed them, I said, "For what? He said, 'Well, I don't know Miss G.' He said they key in something and they don't

fix the price. When they punch in everything it comes up what they have to charge us – that’s what he said. So what they ended up telling me was I had used up my [\$1200] amount by May. So from May to the end of December, I had to pay my medicine outright.”

When the focus group moderator asked her how much she was spending for medications over this seven-month time span, the participant offered the following:

“Oh, I have spent so much on medicine. And I go to Eckerd’s Pharmacy to get my [prescriptions] – and it’s a good thing I did because I think J.C. Penney bought out Eckerd or something. So I already had a J.C. Penney card – that’s the only way I can get my medicine. I have to charge it on my J.C. Penney’s card....But that’s the only way I can get my medicine. When I got out of the hospital last year, I had to get one medicine. That one medicine alone was \$140 and [my HMO] wouldn’t pay for it, so I had to pay for it myself. And, you know, this medicine is so outrageously expensive you can’t continue to pay for medicine like that, you know, on a limited income, because you have other things to pay for. The medicine is just outrageous.”

The writers would hesitate to recommend any of the above-noted approaches as adequate “solutions” to the challenges faced by Medicare managed care enrollees. Yet we recognize the positive side to these stories is that these individuals still had the wherewithal to seek alternative means of receiving care, whether through their own financial means, assistance from a personal physician, Veteran’s benefits, and the like. Far too often, though, we encountered beneficiaries who had three strikes against them: their medical conditions were quite severe; they had neither financial resources nor advocates (family members, personal physicians) who could help them get services that the plans would not cover; and many had no sense of empowerment to fight for what they needed.

Beneficiaries with Serious Health Care Needs and No Means for Obtaining Care

In all four cities, we spoke with M+C enrollees who were receiving no treatment at all for their medical condition(s). In some cases, the beneficiaries had fought with their managed care plans before resigning themselves to the fact that the plan would not cover the services. Unable to envision other ways to get the services, these beneficiaries simply “did without.” In other instances, participants reported being “afraid” to question the plan’s decision, and never sought to get that decision overruled. They, too, “did without.” All too often, however, we came across individuals who simply assumed that their longstanding condition would not be covered by the plan, could see no alternative treatment options, and thus had resigned themselves to a lifetime of coping with a disability. One gentleman in Miami offered the following story:

“I’m relatively lucky because I’m in pretty good health. I’m disabled because I was in an accident almost eleven years ago. I was hit by a car on a bicycle and it snapped my leg in two. So I’ve been disabled since then and I collected Social Security Disability and for a while, I was in no [managed care] plan at all. Then I got into Medicare Blue Cross/Blue Shield and I slipped and fell outside of my house one evening on the dew ... and I hurt that leg. And I was laid up for a couple of days. ...But it was several days before I was able to go to the doctor to get a referral for them to just look at me. I went to the orthopedic specialist and

he wanted to know what happened to my leg. “What country did they set that leg in?” And when I told him who the doctor was, he was like – he was taken aback. He couldn’t believe the job that he did. So the doctor was going to perform surgery to have my leg where it had been almost, 90% whole. It was going to take about a year and a half for the three or four surgeries and stuff. Blue Cross/Blue Shield wouldn’t pay for it. ... [My doctor] sent me to that specialist and Blue Cross/Blue Shield didn’t want to pay for the visit to a referral because they said I didn’t just do this. This was an old [pre-existing] injury. But I slipped and hurt my leg and, see, just think - at that time Blue Cross/Blue Shield was making a fortune off of me because I never went to the doctor. I’m in relatively good health except I don’t get around very well. That’s my leg. I don’t know if you’re interested in looking at it but it’s terrible.”

He then pulled up his pant leg to reveal a leg that at best could be termed “mutilated”. The skin around the middle of his shin was red and swollen, and it appeared that part of the tibia was actually pressing outward into the skin. It was not hard to see why his specialist had gasped at the site, and had wondered what third-world country this man had been in when the leg was set. Because his previous managed care plan had denied this gentleman the medically necessary treatment that he believed would allow him to return to the work arena, he had switched to a new Medicare managed care plan. Nevertheless, when the moderator asked if he had looked into whether this new plan would pay for the needed surgery, he replied that he had not and seemed resigned to the belief that the new plan would be no different than his previous one:

“I haven’t looked into it and I don’t know if they would or not. I’m forty years old; I just turned forty in the beginning of the year. I’m still relatively a young man. I could still work and I’d like to work. ...I would like to get my leg fixed.”

Importantly, other participants in the focus group had found alternative means (other than their managed care plan) of getting their treatment needs met, and they rallied on this gentleman’s behalf. From offering him names of orthopedic surgeons to suggesting that he try a different Medicare HMO plan, the group encouraged him to fight for the care he needed. This pattern – ill-but-untreated individual, supported by other participants in the focus group – repeated itself at every site in which we conducted groups. This dynamic is discussed in greater in the concluding chapter of this report as a way in which CMS can improve Medicare HMO enrollees’ access to services.

Summary

The original impetus for conducting focus groups was to ascertain the barriers to services faced by Medicare HMO enrollees who are members of specific subgroups, including African-Americans, Hispanics, senior enrollees in fair or poor health, and enrollees who are under age 65 and disabled. A critical finding from the group narratives was that participants *did not define their Medicare managed care experiences within our framework*. Rather, the challenges of managed care are quite involved, and appear to result from a combination of the following:

- ◆ enrollee’s health status (e.g., extent to which s/he needed medical services); and

- ◆ plan benefits and overt/discreet barriers to service (e.g., long on-hold periods on the phone, slow payments to physicians, difficult referral process);
- ◆ enrollee's financial well-being (generally "limited" for HMO enrollees);
- ◆ additional resources (advocacy, family support) that an enrollee has to help him/her get the medical support s/he needs.

The complex interrelationship between these factors suggests that there is no "quick fix" for Medicare managed care enrollees. Any proposed ameliorative measures must take into account the myriad dimensions that may be affecting an enrollee's experience with his/her managed care plan, from his/her financial status to the degree to which the enrollee can advocate on his/her own behalf. The life-experiences of "Jim," a focus group participant from New York City, firmly illustrate the potential level of need – and the level of existential distress – that some senior members of our population face, and who could only benefit from increased levels of outside support.

Jim was a seventy-five year old man who had struggled much of his life, and was continuing to struggle at every turn. He had worked all of his life, but for companies that paid him little, that downsized and laid off workers frequently, and that offered few or no health benefits. He had serious medical conditions for which he needed reliable health insurance. The recent deaths of his wife and his mother meant that Jim had lost his strongest social support network. And, because he and his wife had been living at his mother's home, and because the house had to be sold upon her death, Jim was looking at an imminent move into a New York City apartment that would consume what few financial resources he had left. His narrative, presented in full below, attests to the needs of members of this population, and how even a "small medical bill" (e.g., \$50) can be potentially devastating under the right – rather, wrong – circumstances:

"Since I've gotten out of school, I had about five or six jobs... I worked for one company about eighteen years, [but] we didn't have no hospitalization, no nothing. And when I was laid off, I came to Brooklyn and I went on welfare. [One program] helped me out and put me to work in the 66th Precinct on Eighteenth Avenue. I worked there three years and then the Program finished and I went on unemployment. My next door neighbor knew I was looking for a job, so in 1981, I went to work at Dell Publishing Company. But then Doubleday sold out to Phantom, [and] Dell put me on a plan for early retirement. So I went at sixty-two instead of sixty-five. Either that or I would have maybe gone on unemployment and I would have lost all my benefits and hospitalization and my wife wasn't well. When I went to work for Dell, they gave me \$130 a week, that was my base pay but I wasn't worried about that because the hospitalization was great; especially for my wife, Margaret. And then I went out on retirement and I worked part-time for Phantom...In 1993 I went for surgery. I had an enlarged gall bladder and I think that was telling me something to stay home with my wife. I retired for good in 1993 and my wife passed away in '95 so I was glad I was able to stay with her. Then in 1998, I'm still staying home and my daughter died at fifty-one of lung cancer. And I'm still by myself. I've lived on East 4th Street fifty-one years; I was married for forty-eight years. My mom and dad lived

upstairs. I looked after [my mother] all these years...and in December, my mother passed away. She was ninety-five and now I'm all by myself.

“I [had] Social Security and [a] pension, which comes to about \$800, which is not much, but ...I have food stamps; they help me out a little bit. And as far as the [Medicare managed care] plan, they help me out a lot [but] I wish they could help me out a little more when I get prescription drugs. I have sometimes, even with my co-payment, eighty, ninety, a hundred dollars which I have to pay... all out of my \$800-\$900 a month. I had a triple bypass surgery in August of 2000. And I'm getting bills from the hospital emergency room. I paid one bill – it was \$50, which wasn't much, but I paid it. Now I have two other bills, \$250 emergency room and I had a triple bypass in August and then I had to go down for stints in my right side because I had blocked arteries; that was in February. Then I had to go back again. I had the same problem on my left side. ... I take nitroglycerine. I take aspirin and another medication that I think I have to stay on the rest of my life. So that's expensive. I wish they could help me out more with my prescription drugs.”

Jim and individuals like him participated in our focus groups at all four sites. They are not just the “dual eligibles” – i.e., individuals eligible for both Medicare and Medicaid – but middle-class persons who were struggling with severe health conditions, and the fixed income that retirement inevitably brings. The implications of these findings are summarized in the following chapter.

Chapter IV – Summary and Conclusions

At first pass, the reader might view the findings from the second round of the MCAHPS subgroup analysis to be contradictory and somewhat confusing. The research literature and expert panel members call for a health service delivery and payment system that takes into account the unique characteristics and needs of each of the four subgroups. Meanwhile, the M+C plans report that those four categories are not meaningful to the operation of their plans, that instead they are focused on the health status of those enrollees who might consume most of the plan's finite resources. And, finally there are the beneficiaries, who report that access to care under M+C plans is a function of a number of variables, including: their health status; their plan's benefit package (and its actual application in the real world); and their own ability to lobby for the care that they need. How can we begin to improve Medicare managed care enrollees' satisfaction with their plans when we are confronted with such disparate perspectives? The research team suggests that the best place to begin is with the perspectives of those who are actually participating within the Medicare managed care arena itself: namely, the M+C plans and the beneficiaries. Representatives of both the plans and the enrollee populations indicated that money is the driving factor within the health insurance arena. Whether they are for-profit entities or not, health plans must play the actuarial game, balancing premiums received against payouts for services, enrolling healthy beneficiaries to compensate for the claims of their less healthy counterparts, and managing enrollees' needs for services against the costs associated with each incident of care.

In some respects, M+C enrollees are forced to play the same game, balancing health care needs and associated costs against their now-fixed retirement or disability incomes. There are numerous health insurance options available to Medicare eligibles, including the traditional 80/20 Medicare plan, as well as the variable-rate supplements offered through the American Association of Retired Persons. In a perfect world, one would surmise that individuals with the most serious health needs would purchase a higher level of insurance coverage in order to meet the anticipated high cost of treatment. In real life, however, there is no such correlation. The majority of beneficiaries with whom we spoke were living on very small, fixed incomes and could not have afforded adequate medical coverage under any circumstances. Most said that they had enrolled in a Medicare HMO because of the lower premiums, the plan's pharmacy benefits, and because, in theory, they knew what their financial responsibility would be for each incident of care. Thus, like the plans themselves, beneficiaries were not looking to get ahead by enrolling in a Medicare HMO; they were just hoping not to fall any further behind.

These findings suggest that efforts by CMS to improve M+C beneficiaries' satisfaction with their plans focus on those dimensions of the managed health care experience that enrollees have defined as problematic. Specifically, enrollees expect that when they have a health condition that requires medical treatment, the managed care plan cover the cost of the necessary services. When those services are denied by the plan, individuals may require assistance either to negotiate the intricacies of a plan's bureaucracy (and get the decision overturned) or to locate an alternative, affordable source of treatment. It is this issue – that of assistance *qua* advocacy – that emerged as most difficult for many of our focus group participants, but that also suggested the most possible solutions. Suggestions were made for solutions to come from the plans

themselves, as well as from individuals outside of the managed care structure. We address both of these arenas in turn.

Plan-Based Solutions

Case Management and Disease Management

Given that the MMC CAHPS data evinced a direct correlation between plan satisfaction and enrollees' health status, one could anticipate that improvements in beneficiaries' health care would lead *indirectly* to an increase in plan satisfaction. Two programs instituted by several of the site visit plans would seem to lend themselves to enhanced consumer satisfaction. Case management, for example, aims to prevent downturns in an enrollee's health by ensuring that preventive and maintenance services are received in a regular and timely fashion. Similarly, disease management programs are oriented at stabilizing the enrollee's health by instituting strategies that can ameliorate the effects of chronic disease conditions. While both case management and disease management are utilized by M+C plans with an eye towards balancing quality care and financial sustainability, these programs should also maintain or improve enrollees' health and, by extension, their satisfaction with their plans.

Clarity in plan benefits

A second concern expressed by beneficiaries was that when they did have a need for services, it was not always clear from the plan materials the benefits for which they were eligible. In some cases, they said, the plan information was in dense, booklet form, and not easily understood by anyone without a law degree; more often, however, enrollees wanted information in a format that was clear, simple, and easy to understand. Beneficiaries who were not native speakers of English requested plan information in their own languages; individuals with visual impairments asked for plan information and updates in auditory or Braille formats; and still others noted that enrollees with cognitive challenges needed to receive benefits information via forms and processes that accommodated their impairments. The request was thus not just that plans disseminate benefits information in a "culturally competent" way, but in ways that could be accessed and understood by enrollees with any number of characteristics and challenges.

In addition, focus group participants in almost every site indicated that, contrary to Medicare policy, plans had a tendency to change their benefits structure mid-year. Beneficiaries were less put off by the mid-year changes, and more by the fact that they would only learn of the alterations once they called to schedule an appointment with a provider or receive a particular, previously-covered treatment. They thus made a unanimous request that any and all changes to the benefits structure be conveyed to enrollees in a timely and user-friendly (see above) manner.

Reasonable response time on phone

Consonant with the above point, beneficiaries reported that when they had a question about their benefits and called the toll-free number to get additional information, the processes through which they had to go to get their questions answered were difficult and involved. In some cases, they said, they had to wander through a maze of push-button options ("for information about X press 1"), sometimes only to get punted to an answering machine or kicked out of the phone queue altogether. Individuals with some cognitive impairments, we were told, had significant

difficulties trying to negotiate the option maze, which required a level of patience and attention to detail and sequencing that many enrollees do not have.

While many enrollees said that they could deal with the telephone hurdles, they were loathe to do so when they failed to reach a “live” person in a reasonable amount of time. Long waiting periods “on hold,” or even abbreviated waiting times to leave an answering machine message were deemed inadequate by most of our participants, who wanted their questions answered in a more timely fashion. Stricter monitoring of help lines, or even more stringent requirements for responding to incoming calls, may help to alleviate some of these concerns.

Plan-Sponsored Peer Communication Events

The focus groups provided the research team with numerous opportunities to observe the wonderful benefits that naturally accrued to individuals who participated in these interactions. Although each group developed its own unique dynamics, in almost every instance certain group participants took on the role of peer supports for others. Sometimes it was a simple dynamic, whereby individuals shared their experiences and their respective approaches to solving a common problem; just as often, though, empowered members of the group took up “the cause” of their less-empowered colleagues, sharing names of physicians who were particularly well-liked, offering ideas about where enrollees could go for possible financial assistance, and even suggesting where individuals might be able to receive affordable treatment when they needed services not covered by the HMO. While this group dynamic partially mirrored that of the “senior ambassadors” program instituted by one of our site visit plans (see Chapter 3), the interactions were also much more than those of the ambassadors program, which was really oriented largely towards peer-supported enrollment. Focus group participants widely noted the power in the group dynamic, and suggested that plans support regular get-togethers by enrollees for sharing of ideas, experiences, and socialization.

Advocacy outside the Plan

Perhaps one of the most important lessons we took from the beneficiaries was that many of them – because of cognitive or other challenges – required someone to advocate on their behalf in order for them to receive the medical care that they needed. In one of the plans we visited, beneficiaries had a card with a picture of their “Dedicated Customer Service Representative,” who was often promoted as the individual who “could answer any questions” and could assist the beneficiary with getting needed services. Given the competing interests of the beneficiaries and the plans – i.e., that both parties are looking to the other to absorb the cost of health services – we believe it to be important for the advocate to be someone not directly linked to the plan itself. The closest example we found of this was at one particular site visit, where beneficiaries had access to an ombudsperson whose job was to report to the county health department.

Conclusions

In sum, we learned from the focus group participants that Medicare managed care beneficiaries as a group can be viewed as a vulnerable population. Despite the fact that many were in relatively good health, they recognized that their advanced age carries with it the potential for a serious health crisis, which in turn could mean financial destitution. They thus viewed Medicare

HMOs as offering the possibility of striking the delicate balance between good health care services and financial integrity – so long as the plans came through during the inevitable health crisis. CMS’ efforts to monitor the M+C plans and enrollees’ satisfaction no doubt must walk this same fine line, ensuring that reasonable health care service is delivered to beneficiaries in a cost-effective manner. The suggestions offered in this report may serve as a first step towards understanding the perspectives of the M+C enrollees, as well as recognizing possible directions that may lead to improvements in the way Medicare beneficiaries are served.