



California Health Decisions

Involving the Public in Health Care Choices

May 23rd, 2000

Dear Friends:

It is my pleasure to present these findings and recommendations from the initial phase of California Health Decisions' (CHD's) Healthcare 101 project. Healthcare 101 is a broad-based educational project designed to increase beneficiaries' understanding of and access to Medicare.

To prepare this report, we relied on Medicare data from an array of local, state and national sources. We also spoke directly with Medicare experts from organizations throughout California and in Washington, D.C. to gain insight into their views, and to hear their assessments of where and how the system needs to be changed. The recommendations at the close of this report reflect their thoughtful advice as well as the data analysis.

CHD has further refined the scope of this campaign to include additional research with providers, beneficiaries, and members of the baby-boom generation. We welcome your comments on this report, as well as your participation in subsequent stages of Healthcare 101.

Sincerely,

Kristen Spalding, MHA, MSG
Director of Strategic Development

Enclosure



*California Health Decisions
Healthcare 101
Today's Medicare Consumer and Provider:
Challenges and Solutions
May, 2000*

Introduction

Healthcare 101 is a long-term initiative organized by California Health Decisions (CHD) and implemented by a broad-based, collaborative partnership dedicated to helping consumers choose and use their healthcare delivery systems. The partnership has focused its initial efforts on making more and better educational resources available to California's growing Medicare population and to the healthcare providers and purchasers who serve them.

California's Medicare population includes nearly 4 million men and women, a full 10 percent of the national Medicare population. Ethnically diverse with widely ranging income and education levels, California's Medicare beneficiaries are decidedly not homogenous. In this report, CHD summarizes two areas of research conducted to guide the Healthcare 101 partnership in helping consumers, providers, and purchasers understand and access Medicare.

The first part of the report distills a series of in-depth interviews CHD held with key individuals who serve the Medicare population. The second portion of the report reflects CHD's analysis of existing Medicare data, drawn from a variety of state and national resources. The full complement of the interviews and data analysis forms the basis for the recommendations that conclude this study.

What the Experts Say

In face-to-face and telephone interviews between December 1999 and February 2000, CHD spoke with twenty-one individuals from a wide array of organizations. These included agencies of the federal government (HCFA), health maintenance organizations (PacifiCare/Secure Horizons), senior advocacy groups (AARP), private foundations, state and local agencies serving seniors in California, as well as education and advocacy organizations targeting specific ethnic groups (Latino Health Access, and the Asian and Pacific Islander Older Adult Task Force). CHD also interviewed ten individuals from the Health Insurance Counseling Advocacy Program (HICAP), who work directly with beneficiaries and are exclusively devoted to advocating on their behalf. Key findings emerging from these discussions are described here.

Recurring Themes

Limited understanding of Medicare coverage and services. Interviewees used terms like "marginal," "minimal" and "poor" in describing beneficiaries' understanding of Medicare coverage and services. At best, perhaps half of the targeted population is clear



on what Medicare covers and how to access care, said one agency director, adding, "That's on a good day."

The most commonly cited area of confusion is coverage for long-term care. Several individuals described seniors as "shocked" to learn that long-term care is not covered. Many spoke about misunderstanding among beneficiaries regarding the 100 day nursing home care provision, and expressed concern that patients and families are often poorly informed when a patient is discharged from the hospital to a nursing home.

"If [beneficiaries] are discharged from a skilled nursing facility or hospital into a rehab center, [they] may still be very sick, and might not be able to take full advantage of the rehab services that they are entitled to," observed one interviewee. "However," she added, "the clock is ticking in terms of their maximum limits paid for by Medicare," a fact that is often unclear to patients and families.

Two other areas of widespread confusion about Medicare are prescription drug coverage and ambulance service coverage. Again the term "shock" came up as interviewees described beneficiaries learning for the first time that they have a chronic condition requiring medication that will not be covered. Another interviewee recounted the common scenario where an elderly person falls, is transported to the hospital, and then does not understand why a bill is received for the ambulance service.

Confusion about Medicare stems from a variety of issues and sources. The reasons interviewees offered most frequently for this lack of understanding included:

- *Confusing, poorly worded, or overly lengthy brochures.* "The [Medicare] handbook can be quite confusing," noted one interviewee from central California. "Most of the literature does not explain that Medicare will not pay for anything unless it is proven that you need skilled care," said another.
- *Tendency among beneficiaries to seek or read information only when they become ill, when they may not be well enough to absorb and process the details.* "Health care literacy is exceedingly low because it's a just-in-time knowledge. [Beneficiaries] don't learn about the options until they need them," according to one of the experts CHD interviewed. Said another, "The problem is that a lot of times consumers try to access the system when they are in a crisis mode. They have just been diagnosed and they want information."
- *Lack of knowledge of Medicare information resources.* Beneficiaries often don't know where to start when they have questions about Medicare. "They want to know who they should ask or where they can go with questions," said an interviewee. Another pointed out that "no strong, central presence" is available to help beneficiaries navigate the Medicare system. Many stressed the importance of personal contact with beneficiaries, and prompt attention to inquiries. "They want a live person to help them through the system," observed one, adding, "Beneficiaries and their caregivers want immediate answers." While several organizations (HICAP, AARP, others) are excellent sources of Medicare information, beneficiaries may not be aware that these sources exist. In addition, the current organizations providing Medicare information cannot address every question from beneficiaries. For example, one interviewee noted that she is frequently asked to help beneficiaries determine which physicians are associated with particular health plans. She neither has this information readily available, nor can she direct beneficiaries to a central resource to find out.



- *Lack of material for non-English speaking beneficiaries.* While Medicare information is available in other languages, several interviewees commented that the translations may not be suitable. "A lot of times we just reproduce the same educational material in different languages and we forget that there are cultural differences in the understanding of the languages. We cannot just make assumptions that information about Medicare can be universally communicated," stated one individual. Terms such as "respite," "long-term care," and "Medicare" do not have meaning to people who speak certain languages and dialects, pointed out an interviewee who works with ethnic populations.

Providers who are asked by their patients to explain Medicare coverage and services lack the time, tools, and information to do so. An interviewee told of addressing a group of physicians and being told very directly that Medicare is confusing. "They kept telling me, 'You have to make Medicare easier to understand.'" She continued, "I have found that providers, like beneficiaries, have little understanding of the program." Her point was echoed by another interviewee who spoke of the "great need for Medicare education for providers." At the same time, many of the interviewees acknowledged the constraints on physicians' time and their need to focus on clinical, rather than insurance, issues.

Beneficiaries do not have tools to evaluate the quality care they receive from Medicare, both traditional and Medicare+Choice. Several interviewees stated that the lack of uniform quality measures makes it difficult, if not impossible, to assess beneficiaries' views on quality of care. "Satisfaction numbers appear high but the measurement tools are questionable," was one comment. Others noted that in general, people who are well report being more satisfied with quality of care than people who access the system more frequently due to illness. "Those who are in good health are happy," she stated.

Beneficiaries in Medicare+Choice plans who are aware of and have accessed preventive services such as mammograms and other routine screenings often perceive the quality of their care as good, according to some of the interviewees. "[Beneficiaries] like the fact that they receive annual check ups," remarked an interviewee. In contrast, Medicare+Choice beneficiaries who report dissatisfaction with quality of care may be complaining about a system they do not understand. For example, interviewees noted that the referral and authorization process confuses many beneficiaries, and they may view the normal turnaround time as "too long." Perceived convenience may color beneficiaries' assessment of the quality of their care, clouding the issue.

When the terms of their Medicare+Choice coverage change, beneficiaries respond with worry and dismay. Several interviewees reported instances where beneficiaries chose plans with the understanding that particular physicians were in the network and specific prescription drugs would be covered. These beneficiaries later learn that a physician has left the health plan and a certain drug is no longer covered. In some cases, the entire medical group no longer exists, reflecting the vicissitudes of the industry. "There is too much flux in prescription drug coverage as well as too much flux in physicians' ability to pull out of a region," stated one individual.



This problem is particularly acute in rural areas, noted several of the experts CHD consulted, leaving beneficiaries with no choice but to travel considerable distances for their care. And, many added, transportation is a major issue for beneficiaries who do not drive or have access to public transportation.

Two interviewees expressed concern about minority beneficiaries with low education levels being "taken advantage of" or falling victim to health plan "scams." The differences between the promises and the plans are frequently dramatic, noted one interviewee. "In the sales pitch [beneficiaries] are offered so many choices, but that's not the reality [of the plan]."

Secondary Research Summary

Ample data corroborates the expert contention that seniors need help choosing and using their health plans. A Field Research Corporation survey documents the difficulty beneficiaries encounter in understanding what is covered by Medicare, the differences between Medicare managed care plans and traditional fee-for-service, and what choices and rights they have. For example, there is poor understanding of coverage for services such as long-term care, second surgical opinion, durable medical equipment, and of recently implemented benefits such as flu and pneumonia shots, according to the Barents Group, a Washington, D.C. research firm.

Research done for AARP by Hibbard et al. reveals that many enrolled beneficiaries could not describe the type of plan they were in, and were unable to distinguish among fee-for-service, a Medicare HMO, or a supplemental policy. The issue of supplemental insurance is a particularly hazy one for beneficiaries, with a significant number unsure of what constitutes supplemental coverage.

Furthermore, according to a *Journal of the American Society on Aging* article, seniors faced with choosing a plan find it difficult to determine:

- How plans treat a particular illness.
- Whether a particular drug is covered.
- How plans provide access to specialists.
- How the plans are rated among Medicare enrollees.
- How many denials of care are appealed.

The enrollment process itself mystifies many seniors, according to research done for HCFA by the Barents Group. Beneficiaries have several basic questions about enrollment, such as whether they qualify for Medicare, and where to go with questions. The language is often obscure to beneficiaries — terms such as "assignment", "deductible", "co-insurance", "network" and "PCP" are unfamiliar.

Barents Group data also concludes that beneficiaries often do not know where to go to obtain information, are frustrated by their inability to obtain the information they want, and seek information that is concrete, useful, and addresses their day-to-day needs.

Target Populations



Older adults with limited education are particularly vulnerable to confusion and misunderstanding about Medicare. The segment of the Medicare population with limited education and below-average reading and comprehension skills is substantial: two of five adults read below the fifth grade level, twice the rate of the general U.S. adult population, according to the Barents Group.

Education levels of minority beneficiaries are significantly lower than the general Medicare population, posing even greater challenges to African-American and Hispanic/Latino beneficiaries attempting to choose a health plan and access care. For example, 37 percent of Hispanic/Latino beneficiaries have completed fifth grade or less compared with 7 percent of the general Medicare population, and four out of ten African Americans have completed eighth grade or less, compared with two out of ten in the general population. Beneficiaries with low education levels tend to rely more on family and friends for Medicare information, and expressed a greater need to feel comfortable with the sources of such information.

The need to target racial and ethnic groups with Medicare education will continue to expand in the future. According to a Henry J. Kaiser Foundation study, the racial and ethnic minority share of the elderly population will more than double by the year 2025, accounting for one in three beneficiaries by that time.

The frail elderly also warrant particular attention when it comes to closing the gaps in understanding about Medicare. With this special population, the majority of whom are women, poor health status may impede their ability to receive and understand information about their health care. Hearing and vision impairments, difficulty performing activities of daily living, and/or problems with mental functioning place even greater limitations on the ability of frail elderly persons to choose and use their health plan.

Provider Education

Focus groups with physicians conducted by the Barents Group illustrated the fact that physicians spend considerable time addressing beneficiaries' questions about Medicare. Questions posed to physicians range from inquiries about what services Medicare covers to beneficiary payment requirements. These questions may also be asked of office staff, or referred to staff by the physician.

It should also be noted that certain segments of the beneficiary population may turn to their physicians more regularly for information about Medicare. A recent survey of California Latino seniors conducted by the Field Research Corporation for the California HealthCare Foundation revealed that 25 percent of respondents regarded their physician as "the most helpful source" of information about Medicare, ranking above other sources such as health plans, AARP, and family and friends.

Physicians participating in the Barents Group research cited the need for more information that would enable them and their office staff members to address beneficiaries' questions. Physicians receive extensive information about Medicare from HCFA and other sources. However, several barriers may prevent physicians and staff from receiving, using, or understanding the material effectively.

During focus groups conducted by the Barents Group, physicians pointed to several specifics they felt would enhance their ability to understand Medicare and



respond to questions concerning the program. They cited the need for general information on Medicare, a primer for new office staff, regular updates via newsletter or other means about Medicare changes, and ready access to HCFA's toll-free number and web site. Physicians may know generally about the toll-free number and web site, but prominent reminders about these sources would help them retrieve information for patients or direct patients to call or check the web site themselves.

Additional tools and information for providers and office staff would address the reality that beneficiaries seek, and feel comfortable receiving, Medicare information from their physicians. At the same time, raising physicians' awareness of the web site, toll-free number, and other information sources, along with developing clear, easy-to-use material for them and their staff will help resolve the concerns physicians expressed about allocating substantial time to answer Medicare questions.

Physicians clearly do not want to be charged with sole responsibility for educating their patients about Medicare. However, they need to know where to direct beneficiaries for answers on:

- Coverage
- Cost
- Appeals
- Whom to call for help
- Primary vs. secondary coverage
- New policies/coverage changes
- Comparison of managed care plans — hospitals, physicians, quality.

Recommendations

The common threads in the discussions with the twenty-one experts and CHD's view of Medicare data in the aggregate give rise to these recommendations for consideration by purchasers, providers, and policymakers. Some of the suggestions are not new. However, the fact that they continue to surface in recent data and emerge spontaneously in conversations with experts is evidence that the proposed ideas merit serious consideration as the driving force behind changes in policies and procedures.

- Create simple, easily-understood tools for consumers and providers. These tools should explain key areas of confusion, such as prescription drug coverage, the "100 day" nursing home stay, referral and authorization, and ambulance service coverage. Medicare information needs to be "bite-sized".
- Establish links among providers' offices and Medicare resources, with training for designated office staff members and access to toll-free numbers and web sites where answers to patients' questions can be promptly obtained.
- Develop synergies among health plans, federal government agencies, and provider groups to produce uniform messages and information about Medicare.



- Specifically, develop objective, standardized information on quality to transform choosing a plan into a thorough and systematic process for beneficiaries.
- Provide a centralized resource for beneficiaries who want help choosing among Medicare+Choice plans. The information they seek, but are unable to find, would outline differences in costs, benefits, and quality of care provided by the plans, using standardized charts or checklists.
- In disseminating these educational tools and messages, include media, individuals, and organizations that will reach special segments of the Medicare population; e.g., frail, homebound beneficiaries and non-English speaking individuals. These may include television and/or videos, church and temple programs, "senior-to-senior" networks to communicate with people for whom personal contact is a priority, home health agencies and workers, and senior centers.
- Create incentives for providers to remain within a network for a specific length of time.
- Use the Internet to target beneficiaries' children, as well beneficiaries who own and use computers, with information about Medicare.

Conclusions

The discussions with Medicare experts and the data analyses underscore that misunderstanding and confusion abound among beneficiaries. Nonetheless, it is important to note that one veteran in the field described "witnessing a trend where people are becoming more knowledgeable." While still poor overall, in her view understanding of Medicare is rising, indicating that prime opportunities exist to reach beneficiaries, providers, and caregivers with more education and information to continue this trend.

Now, the challenge is not only to expand Medicare education for beneficiaries and providers but, as one expert thoughtfully put it, to identify and create the ideal "teachable moments." Before the appropriate messages and media are selected and rolled out, the timing and venues for Medicare education for beneficiaries, their children, and their providers merits re-examination.

As the over-85 population grows and enjoys greater longevity, and in expectation of the first wave of baby boomers qualifying for Medicare in 2011, now is the time to engage consumers and providers in a process designed to increase their awareness of and ability to access Medicare.



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