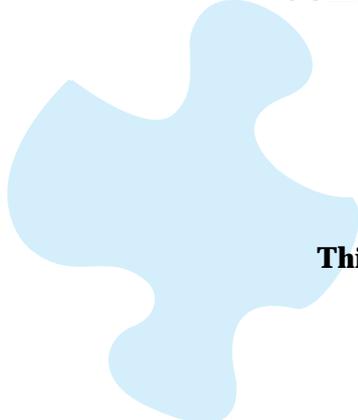


# **Dementia and Medicare Managed Care:** A Growing Challenge for Health Plans



**Naomi Karp, J.D.**

**American Bar Association  
Commission on Legal Problems of the Elderly**



**This research and report were supported by a grant  
from The Henry J. Kaiser Family Foundation.**

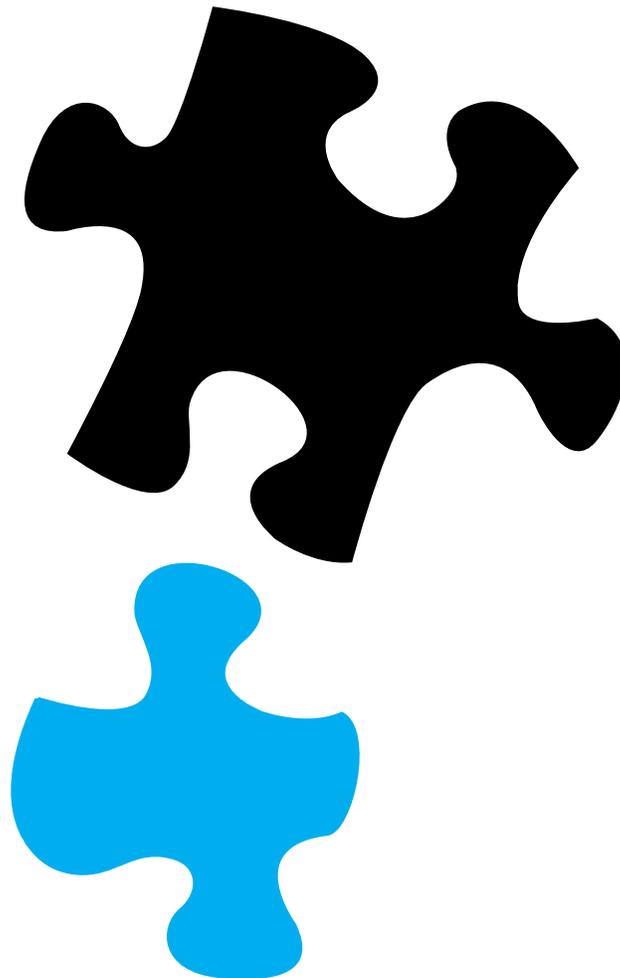
February 2000

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This report was developed with support from the Henry J. Kaiser Family Foundation and funded under grant 97-1995C.

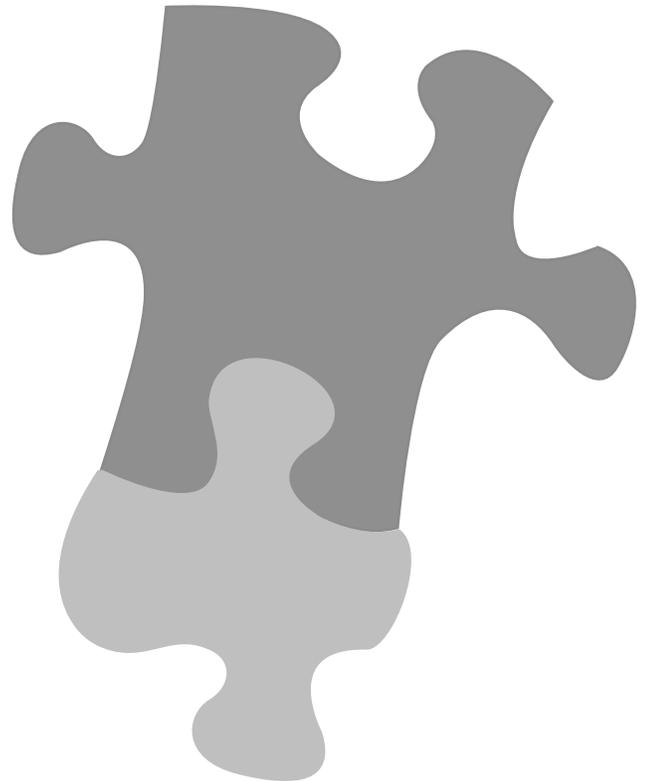
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## ACKNOWLEDGMENTS

I am thankful to the people who reviewed this report, including: my colleagues at the American Bar Association Commission on Legal Problems of the Elderly, Erica Wood, Leslie Fried, and Nancy Coleman; Sally Hurme at AARP; and Katie Maslow and Debra Cherry at the Alzheimer's Association. Without the support of the Henry J. Kaiser Family Foundation, this study would not have been possible. Specifically, I am grateful to Patricia Neuman of the Foundation for her valuable comments and suggestions. Thanks also to Kristin Meyer and Julie Pasatiempo at the ABA Commission on Legal Problems of the Elderly for technical assistance. Finally, I thank the health plans, SHIP counselors, ombudsmen, legal services attorneys, HCFA staff and others who provided me with the interviews and data that form the core of this report.

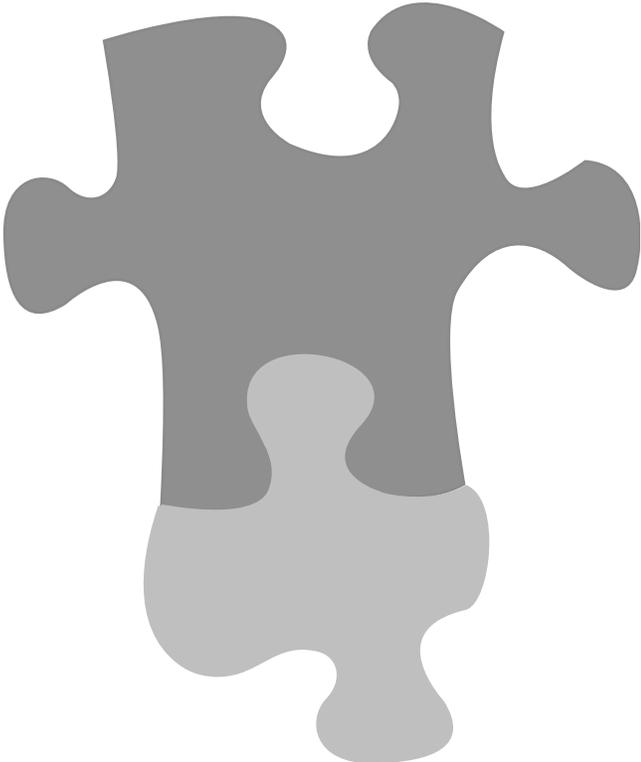




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# Executive Summary

The number of Medicare beneficiaries enrolled in managed care has been surging over the past six years. At the same time, the population at risk of developing dementia has been growing. The confluence of these trends raises critical issues regarding the needs of this population in a managed care environment.

Many health maintenance organizations (HMOs) have little experience enrolling and serving an older population that may have cognitive impairments as well as chronic illnesses. The Health Care Financing Administration (HCFA), which regulates and monitors the Medicare+Choice program, has only recently begun to evaluate policies regarding marketing, enrollment, and service to this vulnerable population.

To gather the perspectives of Medicare+Choice organizations on enrolling and delivering services to Medicare beneficiaries with dementia, the Kaiser Family Foundation and the American Bar Association Commission on Legal Problems of the Elderly conducted a survey of eight Medicare+Choice organizations. While the plans participating in the survey are diverse in their location, size, and delivery systems, this survey was not nationally representative. It aimed to begin the exploration of these important issues.

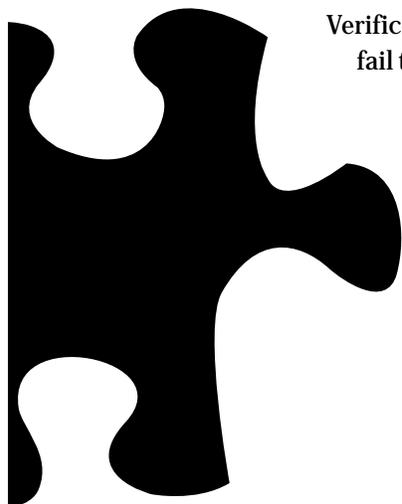
The survey focused on six key areas: marketing, enrollment, health assessments, health care delivery, advance directives, and the identification and role of surrogate decision-makers. This report examines plan responses to survey questions in light of federal and state law, and HCFA policy.

Key study findings include:

- **Marketing and enrollment.** HMO sales representatives receive minimal training on normal changes of aging and cognitive impairments. While their marketing agents sometimes recognize that a potential enrollee may not have the cognitive ability to understand what it means to enroll in an HMO, health plans report that they rarely encounter these situations. Given the prevalence of dementia in the older Medicare population, this finding raises the question of whether plan marketers are equipped to recognize impaired beneficiaries. When marketing agents do question a potential enrollee's decision-making capacity, they seek to involve family members in enrollment discussions. Health plan personnel seem unfamiliar with the complex array of legal mechanisms conveying decision-making authority to family members and others. As a result, they may be unclear about who may sign an enrollment form on behalf of a beneficiary with dementia.

Verification procedures to identify enrolled beneficiaries lacking understanding of plan rules may fail to screen out inappropriate enrollees.

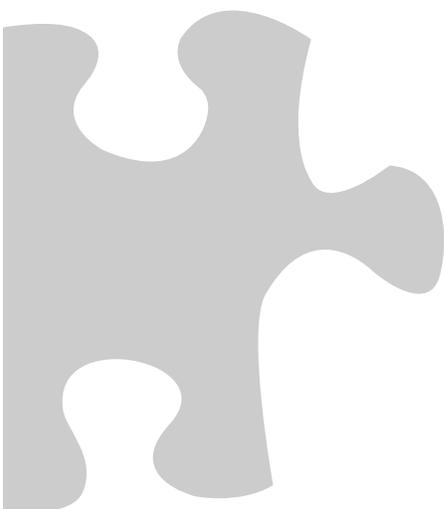
- **Health assessment and treatment.** Medicare HMOs use written self-assessment questionnaires for baseline health screening of enrollees, but these questionnaires are not likely to yield information about possible dementia. While many HMOs do not routinely screen older members for dementia, some Medicare HMOs are beginning to place a greater emphasis on dementia diagnosis and care. Several plans in the survey described initiatives ranging from provider training and clinical practice guidelines to case management and care coordination.



- **Advance directives and surrogacy.** HMOs provide members with written information about planning for incapacity using advance directives at the time of enrollment. However, many lack coordinated methods of documenting advance directives or sharing such information within the provider network. Some health plans also lack procedures for sending correspondence, including determinations on whether particular care will be provided, both to enrollees and to their surrogate decision-makers. Thus, when enrollees with dementia can no longer make their own decisions, their surrogates may be unaware of HMO actions and decisions, and may have difficulty accessing the grievance and appeal system.

While this study provides a “snapshot” of how Medicare+Choice plans currently approach beneficiaries with dementia, many questions remain. Health plans, HCFA, consumer advocates, and professionals in the aging field can work together to understand the complex interplay of law, medicine, and Medicare policy to improve services for this vulnerable population. How can HMOs ensure that cognitively impaired beneficiaries have the protection of an appropriate surrogate in enrollment and subsequent health care decisions? How can health plans and members plan for the possibility that they may become incapacitated and need surrogate decision-making in the future? How should HMOs provide early diagnosis and appropriate care for Medicare beneficiaries with dementia? How can HCFA enhance the ability of Medicare+Choice plans to appropriately identify and serve cognitively impaired beneficiaries? Are changes in state or federal law needed? These are some of the questions remaining for study and discussion.

The survey did identify some promising practices that are under discussion by experts and are emerging at some managed care plans. These practices include: training marketing agents and administrators on the issues and challenges facing persons with dementia; conducting population-based screening for dementia; developing protocols for serving members with dementia and their caregivers; and enhancing awareness about and documentation of advanced directives among plan personnel, providers, members, and caregivers.



**M**edicare beneficiaries have important choices. They can join a managed care plan or remain in traditional fee-for-service Medicare. In some geographic areas, they can choose between competing Medicare+Choice plans. Once in a plan, they must make decisions about health care treatment. If they are dissatisfied with the care they are receiving, they must decide whether to remain in the plan, disenroll and switch to another plan, disenroll and return to fee-for-service, or file a grievance or appeal.

The choices are daunting. The number of individuals faced with these choices is huge—and growing. As of August 1999, over 39 million seniors and persons with disabilities were enrolled in Medicare. Of these, 6.3 million chose to enroll in a Medicare+Choice plan. They represent about 16 percent of total Medicare beneficiaries. Total Medicare managed care enrollment has more than doubled in the past four years. Although the growth rate slowed down in 1999, growth in Medicare+Choice still exceeds the rate of growth in the number of beneficiaries entering the Medicare program. This growth rate has continued, despite the highly publicized plan withdrawals from the Medicare program. In each of the past two years, only about one percent of Medicare+Choice enrollees were left with no Medicare+Choice options.<sup>1</sup>

Concurrent with the surge in managed care is the expansion of the population at risk of developing cognitive impairments. As of 1995, 30% of Medicare beneficiaries were age 75 - 84 years, and 11% were 85 years or more.<sup>2</sup> The numbers of these beneficiaries will increase as the older population itself gets older. Indeed, the number of “old-old,” age 85+ in the United States is growing especially rapidly.<sup>3</sup> By 2030, the population aged 65 years or older is expected to reach 70 million, more than double the number in 1998.<sup>4</sup>

While a decline in mental function is not part of the normal aging process, the likelihood of dementia or related brain disorders increases with advancing age. An increasing number of elders may live beyond their capacity to care for themselves and manage their affairs. Dementia is an umbrella term used to describe the loss of cognitive or intellectual function. Many conditions can cause dementia including Alzheimer’s Disease, depression, drug interaction, Parkinson’s, and other diseases. Alzheimer’s Disease is the most common form of dementia. An estimated 4 million Americans have Alzheimer’s Disease, most of whom are age 65 or older, and the risk of

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<sup>1</sup> <http://www.hcfa.gov/medicare/mc00anal.htm>.

<sup>2</sup> H. Komisar, et al., *Medicare Chart Book* (Washington, DC: The Kaiser Medicare Policy Project, June 1997), 5.

<sup>3</sup> American Association of Retired Persons and Administration on Aging, U.S. Department of Health and Human Services, *A Profile of Older Americans: 1999* (Washington, DC: American Association of Retired Persons, 1999).

<sup>4</sup> *Ibid.*

developing the disease increases with age. By the middle of the 21st century, as many as 14 million may be affected by Alzheimer's as medical technology and lifestyle changes increase the number of old-old.<sup>5</sup>

The confluence of these trends brings thorny and as yet unexamined questions: Who determines whether an individual has the capacity to make choices about health insurance? What happens when a Medicare beneficiary is incapacitated and cannot make the decisions? Who will decide on his/her behalf? How will this be communicated to medical providers? What if the individual is in a "gray area" in which decisional capacity is partial or fluctuating? What are the rights of families making choices for incapacitated individuals? What must families and other surrogates know, and what must they do as decision-makers? How should plans respond to possible incapacity? What is — or should be, or should not be — reflected in the medical record about incapacity and surrogate decision-making? What education is needed for plan personnel, providers, families, and advocates? What actions should the federal government take as these questions become more common?<sup>6</sup>

## A. Goals of the Study

With the growth of managed care and the expansion of the population with cognitive impairments, it becomes important to assess the special protections and services that Medicare beneficiaries need in the managed care environment, and to examine how Medicare+Choice organizations currently serve that population. The Health Care Financing Administration's (HCFA's) policies clearly affect how health maintenance organizations (HMOs) approach older adults with dementia. This study aims to examine HCFA's policies, gather the perspectives of selected Medicare+Choice organizations, and consider the implications of these policies and activities for cognitively impaired Medicare beneficiaries in managed health care. It focuses on six key areas:

- **Marketing.** Do HMO sales representatives receive training on normal changes of aging and cognitive impairments? Should they? How can marketing agents ensure that they don't discriminate against beneficiaries with disabilities? How, on the other hand, should they avoid enrollment of those lacking capacity to contract for managed care?
- **Enrollment.** Are HMOs enrolling Medicare beneficiaries who lack the cognitive ability to make an informed decision on whether to choose a Medicare+Choice plan? Who is authorized to sign an enrollment form on behalf of an incapacitated beneficiary? Do plans have post-enrollment verification procedures to confirm that new enrollees truly understand the enrollment decision? What procedures might work best?
- **Health assessments.** Do Medicare+Choice organizations screen new enrollees for possible signs of dementia? Do primary care physicians understand dementia and its diagnosis?
- **Treatment plans and health care delivery.** Do HMOs have protocols for dementia care or systems for long-term management of this patient population? Do plan providers have the requisite expertise? When beneficiaries enter long-term care facilities, do plan providers or care managers remain involved in their care?
- **Advance directives.** Do HMOs inform enrollees, staff, and the community about advance directives, as required by the Patient Self-Determination Act? Do plan providers discuss advance directives with patients? Does the health plan promote systematic documentation of a member's advance directive?
- **Identification and role of surrogates.** If an enrollee becomes cognitively impaired, do health plans identify and recognize surrogates who can make health care decisions and handle communication with the HMO? Do surrogates receive important notices involving benefits and services? Can a surrogate file an appeal or grievance on behalf of an enrollee?

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<sup>5</sup> In addition, more persons with developmental disabilities, head injuries, mental illness and mental retardation are surviving into middle age and old age. Large scale deinstitutionalization of these special needs populations has meant an influx of persons into the community who may be unable to make decisions and care for themselves. While this report primarily concerns dementia among older Medicare beneficiaries, these other conditions also cause cognitive impairment and effect growing numbers of Medicare beneficiaries.

<sup>6</sup> For a preliminary exploration of these issues, see N. Karp and E. Wood, "Incapacity and Medicare Managed Care: Enrollee Health Care Decision-Making," unpublished paper for Alzheimer's Association (April 1998).

## B. Methodology

To assess health plan perspectives on serving this vulnerable population, the ABA Commission conducted detailed interviews with a range of staff members and providers at eight HMOs participating in the Medicare+Choice program. The Commission conducted these discussions between March and July 1999, and all interviews were in person, with the exception of two telephone interviews. At six of the eight HMOs, Commission staff interviewed a range of personnel, while at two health plans information was provided by a sole staff member. Interviewees at the health plans included Medicare program directors, directors of public programs, member services directors, marketing managers, outreach coordinators, medical directors, geriatricians, geriatric nurse practitioners, and utilization management directors. The Commission staff assured interview subjects that the identities of participating HMOs would remain confidential. Several of the HMOs provided researchers with enrollment and new member materials, evidences of coverage, health assessment tools, and other relevant documents.

The health plans that participated in the study are diverse. Three are located in the Mid-Atlantic region, two in the Midwest, one in the South, one in the Northeast, and one on the West Coast. The number of Medicare+Choice enrollees in the plans ranges from 4,000 to 250,000. All but one have other product lines, such as commercial health insurance and Medicaid coverage. The HMOs are evenly split between for-profit and nonprofit. All are Medicare+Choice coordinated care plans—seven are HMOs and one is a provider-sponsored organization (PSO). Some use a large network of independent providers and medical groups, while some rely on one large medical group to deliver care.

To supplement the health plan interviews, project staff consulted policy and project staff of the Alzheimer's Association, both in its Washington, DC office and at local chapters; state health insurance and assistance program (SHIP) counselors; a Medicare managed care ombudsman; legal services attorneys and other consumer advocates; and HCFA staff. In addition, project staff analyzed the Medicare+Choice regulations promulgated to implement the Balanced Budget Act of 1997, and reviewed HCFA guidelines on marketing, benefits, and grievances and appeals.

Little is known about the nexus of incapacity and Medicare managed care—and how health plans can best meet the needs of this burgeoning population. This exploratory study aims to raise critical issues and heighten awareness for both health plans and policymakers.

## C. Legal Background

Before examining how Medicare+Choice plans should interact with and serve beneficiaries with cognitive impairments, some essential legal background is needed. Health care decision-making law intersects with federal Medicare law. A look at both areas of law sheds light on the issues.

### 1. State Health Care Decision-Making Law

Health care decision-making law is primarily governed by state law. If an individual lacks the ability to make informed decisions and knowingly consent to health care, state law defines who may consent on his or her behalf. States define “incapacitated person” differently, but a recent model law defines an incapacitated person as “an individual who, for reasons other than being a minor, is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance.” (Uniform Guardianship and Protective Proceedings Act 1997)

State laws or legal mechanisms defining who may make health care decisions on behalf of an incapacitated person include the following:

- **Living wills.** These are written statements spelling out an individual's instructions about treatment, or about the withholding or withdrawing of treatment in the event he/she has a terminal condition or is permanently unconscious. Forty-seven states and the District of Columbia have living will laws; and all states recognize them.<sup>7</sup> Standing alone, a living will is a very limited document, since it usually applies only to end-of-life decisions, lacks specificity, and is simply a piece of paper without an agent to bring it to life and to advocate on the person's behalf.
- **Health care powers of attorney (health care proxies).** These are documents appointing an agent to make health care decisions in the event that an individual is unable to do so. The possible decisions the agent can make are not limited to end-of-life choices. The agent makes decisions based on the wishes of the individual when known, and his/her "best interests" when wishes cannot be determined. All 50 states and the District of Columbia have health care power of attorney statutes.<sup>8</sup> Many states have adopted special forms for appointing a health care proxy.
- **Comprehensive health care advance directives.** These documents combine the living will and the health care power of attorney in one document. Currently, 16 states have such a combined health care advance directive.<sup>9</sup>
- **Health care consent statutes.** These come into play when the incapacitated person has no advance directive and needs a health care decision. In the past, physicians often informally relied on family members to make health care decisions, and this still is common practice. Now 35 states and the District of Columbia have enacted statutes specifically authorizing family consent.<sup>10</sup> These statutes usually set out a priority order in which surrogates are authorized to act, e.g. spouse, then adult children, then parents, siblings and other relatives.
- **Powers of attorney.** These are written documents in which an individual grants authority to an "agent" to act on his/her behalf. They normally authorize the agent to manage the individual's finances and property, and generally are not tools for health care decision-making. However, some powers of attorney may be broad enough to encompass decisions about managed care contracts. Durable powers of attorney remain valid after the individual becomes incapacitated.
- **Guardianship.** This is a last resort for health care decision-making if there are no advance directives and no family surrogates. A court gives a guardian the duty and power to make personal and/or property decisions for an incapacitated person. All states and the District of Columbia have adult guardianship statutes. Guardianship removes the individual's basic rights and fundamental liberties, and can be expensive and time-consuming to obtain and maintain.
- **Representative payees.** These are not health care decision-makers. A representative payee is authorized by the government to receive and cash public benefit checks and manage the public benefits for a beneficiary deemed incapable of doing so.

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<sup>7</sup> Charles Sabatino, *Health Care Surrogate Decision-making Legislation* (Washington: American Bar Association Commission on Legal Problems of the Elderly, 1999).

<sup>8</sup> Ibid.

<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

While health care decision-making primarily is governed by state law, the Patient Self-Determination Act is a federal law requiring hospitals, nursing homes, home health agencies, and HMOs participating in Medicare or Medicaid to provide information on advance directives. See Section II(C) below.

## 2. Medicare Provisions

The Medicare statute and regulations say very little about incapacity and how it affects enrollment, disenrollment, decision-making by or on behalf of enrollees, filing grievances and appeals, and other actions in connection with participation in the Medicare+Choice program. A general regulatory framework for those “decision points” in the Medicare+Choice process is as follows:

- **Enrollment and disenrollment.** Individuals may elect a Medicare+Choice plan if they are entitled to Part A Medicare and are enrolled in Part B, do not have end-stage renal disease, reside in the plan’s service area, sign a form and provide required information, and agree to abide by the Medicare+Choice organization’s rules.<sup>11</sup> HMOs must enroll Medicare beneficiaries who want to enroll, regardless of health status.<sup>12</sup> Until 2002, beneficiaries can enroll and disenroll at any time; lock-in periods begin to apply in 2002. A beneficiary starts the enrollment process by submitting an election form to the HMO. Persons who assist beneficiaries in completing forms must sign the form and indicate their relationship to the beneficiary.<sup>13</sup> HCFA will grant a retroactive disenrollment only when there never was a legally valid enrollment or a valid request for disenrollment was not properly processed.<sup>14</sup> An enrollment is not legally valid when the enrollee lacked intent to enroll, as evidenced by an enrollment form signed by a member when a legal representative should be signing for the member.<sup>15</sup>
- **Appeals process.** A Medicare+Choice enrollee may file an appeal when he or she is dissatisfied with a Medicare HMO’s decision, called an “organization determination.” Organization determinations include the Medicare+Choice organization’s actions regarding: (1) payment for emergency or urgently needed services; (2) payment for other health services by non-plan providers that the enrollee believes should be covered; (3) denial of services the enrollee believes the plan should provide; and (4) discontinuation of a service that the enrollee believes is medically necessary.<sup>16</sup> The five steps in the appeals process include internal plan reconsideration, review by an independent outside entity (under contract with HCFA), and further review by an administrative law judge, the HHS Appeals Council, and federal court. The regulations specify time frames for decision-making at each level. An expedited process for organization determinations and reconsiderations is available when the normal time frame could seriously jeopardize the enrollee’s life, health or ability to regain maximum function.<sup>17</sup> Enrollees may authorize a representative to obtain an organization determination or handle any of the levels of the appeal process.<sup>18</sup>
- **Grievance process.** Medicare+Choice organizations must have meaningful procedures for timely hearing and resolution of grievances between enrollees and the organization or its providers.<sup>19</sup> Grievances, disputes not related to payment for or denial of services,<sup>20</sup> include complaints about physician demeanor, adequacy of facilities, and waiting times, among other issues.

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<sup>11</sup> 42 CFR §422.50.

<sup>12</sup> 42 CFR §422.110.

<sup>13</sup> 42 CFR §422.60(c).

<sup>14</sup> 42 CFR §422.66(b)(5).

<sup>15</sup> HCFA Operational Policy Letter #100, Section 4.6 (OPL 99.100).

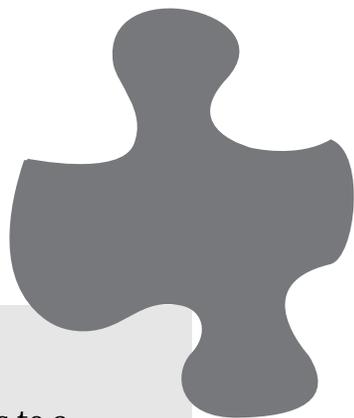
<sup>16</sup> 42 CFR §422.566(b).

<sup>17</sup> 42 CFR §422.570(c)(2)(i).

<sup>18</sup> 42 CFR §422.561.

<sup>19</sup> 42 CFR §422.564(a).

<sup>20</sup> 42 CFR §422.561.



**M**rs. A goes to a presentation by FirstCarePlus, a managed care plan, at her local senior center. She attends day care there, while her daughter is at work. She is confused about what managed care is, and how it relates to her Medicare coverage, but everyone is very enthusiastic about the presentation. When the lady making the presentation approaches Mrs. A with an application form she signs it. Her daughter knows nothing about it until Mrs. A. starts getting all sorts of letters and notices in the mail. In the meantime, Mrs. A has been to see her cardiologist and her ophthalmologist, neither of whom is in the FirstCarePlus network of providers.

## A. Marketing and Enrollment

In the enrollment process, Medicare+Choice organizations may not discriminate on the basis of disability, including cognitive impairments.<sup>21</sup> Yet at the same time they must not enroll a person incapable of understanding what enrollment means. Enrollment by an incapacitated person results in an invalid contract.

The regulations provide that Medicare+Choice organizations must “establish and maintain a system for confirming that enrolled beneficiaries have, in fact, enrolled in the Medicare+Choice plan, and that they understand the rules applicable under the plan.”<sup>22</sup> Such a verification system may serve to confirm that the beneficiary had the cognitive capability to enroll in managed care.

If the beneficiary does not understand what it means to enroll in a Medicare+Choice plan, may a surrogate enroll on his or her behalf? Federal law does not address this issue. HCFA’s policy is that the authority of persons other than the beneficiary to enroll or disenroll is dependent on state law. HCFA states that persons who may sign an enrollment form or disenrollment request include court-appointed legal guardians, persons having durable power of attorney for health care or designated in a written advance directive.<sup>23</sup> Other types of surrogates—such as persons appointed under a durable financial power of attorney and family members pursuant to state family consent laws—are not mentioned in HCFA’s policy. Representative payees designated to receive Social Security payments lack the requisite authority to enroll or disenroll beneficiaries. If someone other than the beneficiary completes an enrollment form or disenrollment request, plans must maintain documentation showing how they determined that another individual was authorized to act on behalf of the beneficiary.<sup>24</sup>

<sup>21</sup> Social Security Act §1852(b); 42 CFR §422.110.

<sup>22</sup> 42 CFR §422.80(e)(2)(ii).

<sup>23</sup> HCFA Operational Policy Letter #100, Section 6.2 (OPL 99.100) (effective Jan. 1, 2000, replacing HCFA Operational Policy Letter #7).

<sup>24</sup> Ibid.

HMO marketing personnel face a significant challenge understanding and navigating these requirements. Distinguishing between normal confusion about managed care and dementia is difficult. Because they receive commissions based on signing up new members, agents have an incentive to make the sale. Non-discrimination requirements push in the same direction. On the other hand, enrolling a beneficiary who lacks the requisite understanding will result in an invalid contract, a member who fails to follow the rules, and the likelihood that the member eventually will disenroll or be involuntarily disenrolled. Enrollment by a proxy also creates complications for the marketing representative. This area of law is far from clear. Without specific guidelines and an understanding of the law, the sales representative understandably may not be able to identify who is or is not authorized to sign on behalf of a Medicare beneficiary.

In this study, we found:

- 1. Sales representatives receive minimal training on normal changes of aging and cognitive impairments.** While marketing agents receive training on HCFA's marketing guidelines, none of the plans in the study indicated that they teach their agents about dementia. Some interviewees mentioned that they learn about physical disabilities, and the need to tailor materials for the population (e.g. minimum of 12-point type size). Some plans recognize that additional training may be needed. One HMO recently identified a vendor that could conduct a "senior sensitivity" course for sales representatives, to include issues of cognitive impairments. At another plan, the medical director stated that they should augment training so agents can learn to distinguish between "hearing impairments and cognitive impairments."

## Texas Court Case Addresses Training of HMO Sales Agents

In a recent settlement with a Medicare HMO, the Texas Attorney General required the health plan to provide training to marketing representatives (1) on the potential for some prospective members to have physical and/or mental infirmities that make them unable to fully understand the ramifications of enrollment, and (2) on the need to terminate marketing activities when it becomes apparent that any of these conditions exist.<sup>25</sup>

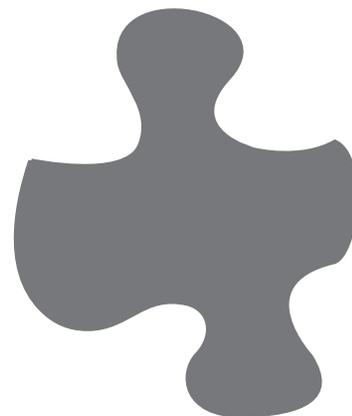
While it may be beneficial for sales agents to have additional training in this area, training alone will not qualify them to definitively determine whether a potential enrollee lacks the requisite decision-making capacity. Plans could consider implementing protocols for marketing representatives to follow if they discern that it may be inappropriate to enroll a beneficiary.

<sup>25</sup> *In re Texas v. PCA Health Plans of Texas, Inc.*, Texas Dist. Ct., 353 Jud. Dist., No. 9712378, 11/3/97, cited in G. Dallek, *Consumer Protections in Medicare+Choice*, report for the Kaiser Family Foundation (December 1998).

2. **When marketing agents encounter potential enrollees with questionable understanding, they generally seek to involve family members or significant others in the enrollment discussion.** Seven of the eight HMOs in the study said that when they encounter a prospective enrollee who seems to have cognitive difficulties, their marketing staff asks the beneficiary if a family member could participate in the enrollment discussion. Some said they would ask the family member if they have a power of attorney (giving them authority to enroll the person in the HMO). One HMO's sales manager explained that the goal of involving a caregiver is to assist and support the potential enrollee, not to "stand in their shoes." In her view, the enrollee still must make the decision.
3. **If the family member does not clarify the situation, some plans will not enroll beneficiaries with dubious understanding.** What does the sales representative do if there is no family member or surrogate to aid in communication or to enroll on the beneficiary's behalf? Three of the plans indicated that they would prefer not to enroll the person if capacity is questionable. One said that it would be better to lose the sale if you were not sure what the person understands. Another stated that they would work with a family member or "bow out gently." These responses raise the question of whether this reaction is discriminatory towards impaired beneficiaries who may benefit from enrollment in managed care.

The commission arrangements between HMOs and their sales agents may provide additional impetus not to enroll a Medicare beneficiary with questionable capacity. The Medicare director at one plan pointed out that if a member disenrolls within the first three months of enrollment, the sales representative loses the commission. Thus, there is no incentive to enroll someone who won't understand plan restrictions, won't be happy in the plan, and may end up quickly leaving the HMO.<sup>26</sup>

4. **HMOs permit an agent appointed under a durable power of attorney for health care to enroll a Medicare beneficiary, but seem unfamiliar with other types of legal authority for enrollment.** Six plan representatives stated that a power of attorney would give someone sufficient authority to sign an enrollment form on behalf of a Medicare beneficiary. Some specifically referred to health care powers of attorney or health care proxies. The election form sometimes explains who may sign on another person's behalf. One form refers to "health care power of attorney," "legal guardian" or "other." Another election form specifies "guardian, conservator or person with power of attorney." A third form fails to specify what authority is required, stating, "If the signature below is other than the applicant's, documentation authorizing the individual to act on the applicant's behalf is attached." Most plans ask for proof of the authorization.



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<sup>26</sup> HCFA's HMO/CMP Manual encourages a compensation system that conditions sales commissions on sustained enrollment of the beneficiary. HCFA notes that it "encourages a marketing agent to engage in full and clear discussion with a potential enrollee during the enrollment process about benefits, restrictions (including lock-in), and other organization rules." HMO/CMP Manual §2212 (HCFA-Pub. 75). This HCFA manual predates the Balanced Budget Act's introduction of the Medicare+Choice program. HCFA is currently drafting a new manual.

State surrogate decision-making law is complex, and there may be others besides guardians and health care proxies with the authority to sign up a Medicare beneficiary in an HMO.<sup>27</sup> Health plan representatives do not appear to be well-versed in these legal issues. For example, one plan's Medicare director stated that a "representative payee" could enroll a beneficiary. In fact, representative payees only have the authority to manage a beneficiary's Social Security or SSI benefits, and explicitly lack the authority for enrollment or disenrollment. When asked what she meant by a representative payee, she took out an "Appointment of Representative" form, used by beneficiaries to appoint someone to represent them in a grievance or appeal. This form is unrelated to the representative payee program. Her lack of understanding of legal terminology and concepts of surrogate decision-making may be common, in light of the legal complexities and minimal guidance from regulators.

## Who Can Enroll a Beneficiary?

A Medicare beneficiary had a durable power of attorney for financial matters and made his lawyer his agent. The beneficiary later became cognitively impaired. When his Medicare HMO terminated its contract with HCFA, his agent sought to enroll the beneficiary in a second Medicare plan. This plan did not accept the enrollment because it maintained that only an agent authorized to make health care decisions could do so. Since a financial agent cannot make health care decisions such as selecting the beneficiary's primary care physician, the financial agent had no authority to make the enrollment, according to the HMO. Yet the authority to enter into a contract ordinarily is one of the powers conveyed in a financial power of attorney. This case illustrates the legal complexities faced by managed care organizations in deciding which surrogates may enroll, disenroll, and make other decisions on behalf of incapacitated beneficiaries.

5. **Health plans report that their marketing agents rarely encounter potential enrollees with questionable capacity to enroll.** Most HMO representatives in the study stated that the question of whether a potential enrollee has the requisite capacity "almost never comes up." Given the prevalence of Alzheimer's Disease and other forms of dementia in the Medicare population, this experience diverges from expectations.

There are several possible explanations for these reported experiences. First, it may be difficult to distinguish between "normal" confusion about how managed care works and confusion resulting from dementia. One medical director stated that about 5-10% of Medicare members go outside the network for care because they do not understand the rules. He posited that this is more likely due to lack of education about managed care rather than enrollee incapacity. Some of the concepts that HMOs identified as difficult for potential enrollees to understand included lock-in; "the fact that they're still on Medicare but can't use their Medicare card anymore;" urgent and emergency care

<sup>27</sup> Health plans seemed unfamiliar with surrogate consent laws, yet 35 states and the District of Columbia have enacted such statutes. These laws enable certain surrogates to make health care decisions in the absence of a written advance directive. The Uniform Health-Care Decisions Act, which six states have adopted and others have emulated in some respects, permits surrogates named in the statute to make health care decisions including "selection and discharge of health-care providers and institutions." (*Uniform Health-Care Decisions Act*, National Conference of Commissioners on Uniform State Laws, 1993) Enrollment in a managed care plan is likely one such health care decision.

Court-appointed legal guardians have reported that some health plan personnel do not recognize the guardian's authority to enroll an incapacitated person in a managed care plan. Guardianship agencies also report that health plans frequently do not send important notices to the guardian, and that plans and providers often make health care decisions without consulting guardians. See E. Wood, *What Are the Effects of Managed Care on Adult Guardianship Agencies and Clients? A Focus Group Report* (Washington: American Association of Retired Persons Public Policy Institute Report #9808, August 1998).

procedures; gate-keeping and referrals; and out-of-area coverage. These concepts can be quite confounding to people accustomed to the fee-for-service system. Having difficulty understanding managed care concepts and vocabulary is so common that it may not be useful as an indicator of cognitive functioning.

A second possible explanation is that Medicare+Choice plans are not directing their marketing activities towards beneficiaries likely to have dementia. A recent study of Medicare HMO marketing practices found that “Medicare HMOs appear to be targeting healthy, active seniors—and not those who are in poor health or who have chronic disabilities.”<sup>28</sup> Beneficiaries with cognitive impairments also may be more restricted in their daily activities, and may be less likely to attend marketing seminars.

Finally, sales representatives may not have sufficient education and training to recognize signs of dementia. Some of the health plans reported the lack of training in this area. Moreover, as one HMO’s medical director put it, even “primary care physicians don’t know how to identify cognitive impairments.” That plan has a high percentage of enrollees with cognitive impairments; given that the plan has only existed for two years and that dementia often develops gradually over time, plan professionals now question whether these members had sufficient capacity to enroll themselves.

- 6. Procedures to verify enrollment may help HMOs identify persons who lack the capacity to enroll, but those processes have limitations.** The Medicare+Choice regulations require plans to have a “system for confirming that enrolled beneficiaries have in fact enrolled in the Medicare+Choice plan, and understand the rules applicable under the plan.”<sup>29</sup> This regulation is similar to the provision in HCFA’s HMO/CMP Manual (predating the Medicare+Choice program) suggesting that plans “establish an enrollment verification system which requires that a different individual from the sales agent call or meet with a Medicare beneficiary who has applied for enrollment to assure that he/she understands such restrictions as the lock-in provision before the enrollment form is finally processed.”<sup>30</sup> Most plans in the study have such a procedure.

Verification call practices varied among the plans in the study. Some procedures are more timely than others. Several HMOs make these “welcome verification calls” within three days, and make several attempts to reach the enrollee. Others call within 30 days. One plan administrator stated that calls should occur before the effective date of membership, but “that is not feasible.” Some plans screen all new enrollees, while others screen only selected enrollees. For example, two plans systematically call only individuals who have enrolled by mail. One HMO’s Medicare director reported that they call a random sample of enrollees as a check on the marketing agents’ performance. At some plans, these verification calls are part of “member retention”—efforts to reach out to members so they won’t disenroll.

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<sup>28</sup> E. Maibach et al., *Marketing HMOs to Medicare Beneficiaries* (Menlo Park, CA: The Henry J. Kaiser Family Foundation, July 1998), 21.

<sup>29</sup> 42 CFR §422.80(e)(2)(ii).

<sup>30</sup> HMO/CMP Manual §2212 (HCFA-Pub. 75).

7. **HMOs in the study report that they do not identify many people with apparent cognitive difficulties through the verification call process.** This is consistent with plans' statements that marketing agents also encounter few potential enrollees with possible dementia. Again, it is hard to know whether there are few cognitively impaired beneficiaries among plan enrollees, whether the desire to attract new enrollees undercuts efforts to screen out inappropriate enrollees, whether the plan employees lack the requisite training to distinguish incapacity, or whether the enrollment and verification procedures do not effectively screen for such beneficiaries. Telephone screening may or may not be effective in identifying dementia.<sup>31</sup>

One HMO shared its verification call script with the Commission. At that plan, an employee described as a "72-year-old sensitive woman" makes all of the verification calls. "She is very good at talking with Medicare beneficiaries," the Medicare director stated. "She picks it up if the person is having problems understanding. She may spend 45 minutes on a call explaining things. She has never had a case where the person just didn't get it. Mostly she finds that seniors have a hard time hearing on the telephone." The verification script covers basic information about the enrollee and plan rules.

### Excerpt from a Medicare+Choice Plan's Verification Script

"Do you understand that if you are presently under a doctor's care, taking prescription medicine or using any durable medical equipment such as oxygen, crutches, etc., you must contact the medical center or primary care physician you selected to make an appointment as soon as possible after your effective date?

Yes  No."

"Do you understand that when you are temporarily out of the [plan name] service area, if you require urgently needed medical care, and you see a physician other than your selected physician, you should call your medical center or primary care physician (or have someone call for you) to report this so we can arrange to pay your bill?

Yes  No."

"Do you understand that if you access unauthorized care, i.e. non-emergency medical services that you receive out of the [plan] network, neither Medicare nor [plan] would pay for your services, you would be responsible for the provider's fee?

Yes  No."

The script asks the new enrollee to answer "yes" or "no" to questions about the plan's details and procedure. This survey format may not differentiate between enrollees who truly understand and those who are just assenting to the statement. Questionnaires that ask enrollees to explain what they would do under different scenarios might be a more valid indicator of understanding.

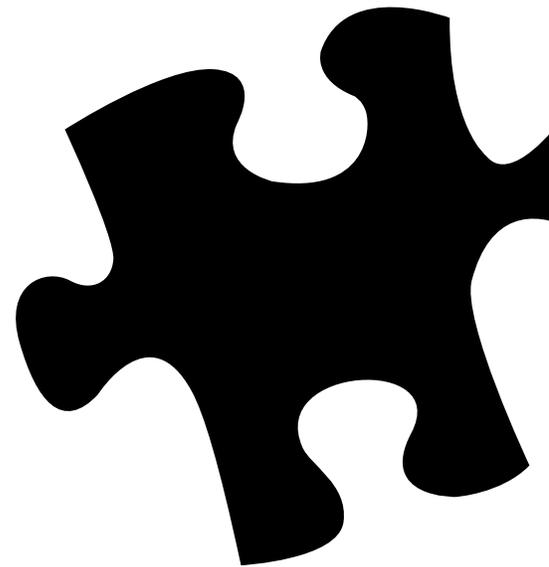
8. **When HMO staff do identify enrollees who lack understanding during the verification call, they seek to involve surrogates and, if necessary, disenroll the beneficiary.** Several plans in the study said they would ask whether a family member has power of attorney, if they believed during the verification call that the new enrollee did not understand what they had signed. That person would be called upon to decide whether to disenroll on the beneficiary's behalf if the enrollment was completed. One HMO's outreach coordinator stated that the verification caller would refer a questionable enrollee's case back to the sales manager for a

<sup>31</sup> Researchers are testing telephone administration of the Mini Mental Status Examination in Minnesota. Correspondence with David Knopman, M.D., August 23, 1999.

## One HMO's Dilemma

An elderly couple is enrolled in an East Coast HMO. The woman has Alzheimer's Disease and a multitude of other medical problems. The man seems to have limited understanding of the rules of managed care. These members repeatedly have used out-of-network services and to date, the HMO has made exceptions and covered the bills. The plan's outreach coordinator arranged for a home visit when the couple's granddaughter was present. The outreach coordinator observed that the granddaughter "has her limitations" as well. The plan has decided to stop paying for out-of-network services because these members "are not good candidates for a 'pay-and-educate' approach." It appears that the members will accrue mounting uncovered medical bills, while the plan searches further for a possible surrogate or explores involuntary disenrollment.

"possible violation." The sales manager would question the sales representative about the individual, and might visit the member. If necessary, the enrollee could be retroactively disenrolled.





**M**r. B has enrolled in Healthy Circle of Care, a Medicare+Choice plan in his city. He is in the early stages of Alzheimer's Disease, but has not been diagnosed. He lives around the corner from his daughter, who comes by every day to bring him groceries, check his mail, and help pay his bills. Healthy Circle of Care sends him a Member Health Questionnaire. His daughter fills it out for him, indicating that he has no acute health problems and has had no recent hospitalizations. Mr. B goes for an appointment with his new PCP, a doctor he has never met before. His daughter drops him off and picks him up, but doesn't come in with him. The doctor spends ten minutes with him, and a nurse takes blood and an EKG. No one asks him about some of the things he has noticed recently—difficulty remembering things, having a hard time playing bridge, inability to balance his checkbook. When he leaves, they tell him to come for another physical next year.

## **B. Health Assessment and Treatment**

Both private pay and managed health care systems face challenges in serving people with dementia. Diagnosis is not easy. Many physicians are not trained in geriatrics. Time for communication between physicians and caregivers is limited. Primary care physicians and HMOs lack comprehensive approaches to geriatric assessment and care management. Many facets of appropriate care do not fit the traditional medical model.

Despite these problems, managed care may be better suited for a coordinated and thorough approach to dementia care than fee-for-service medicine. The Alzheimer's Association is working with Medicare HMOs and care providers on an initiative to make managed care work for people with Alzheimer's Disease and other dementias. Collaborators in these efforts have identified nine essential components of high-quality Medicare managed care for people with dementia:

- Provider training on dementia and how to care for people with these conditions
- Identification procedures for enrollees who need a diagnostic evaluation
- Diagnostic protocols
- Procedures for involving caregivers
- Information for patients and families about dementia, and treatment and care options
- Single point of contact for patients and families
- Ongoing treatment for dementia and coexisting medical conditions
- Support groups and supportive counseling
- Referrals to home- and community-based services.

Medicare managed care demonstration projects involving Alzheimer's Association chapters are operating in at least 15 sites around the country. Seven sites are testing the Chronic Care Networks for the Alzheimer's Disease model designed to be feasible for real world health care systems and to take advantage of the incentives created by risk-based financing.

The model includes a three-step patient identification process to identify individuals who should receive a diagnostic assessment with a specific diagnostic protocol. Following diagnosis, the model includes care management blueprints, considerations in caring for people with coexisting medical conditions, and family caregiver information and support.<sup>32</sup>

A second model, the Health Resources and Services Administration and Administration on Aging Model, is being tested in five locations. Individuals with dementia and their family caregivers are randomly assigned to treatment and control groups. The control group gets “usual care” from their HMO, while the treatment group gets information, counseling, referrals for community services and subsidized respite care.<sup>33</sup> There are several other individual projects involving local Alzheimer’s Association chapters and Medicare HMOs. These pilot projects should yield information on whether the managed care setting offers opportunities to improve dementia care.

Our study examines several facets through which Medicare HMOs currently diagnose and treat enrollees with dementia.

- 1. HMOs use a written questionnaire to be completed by the enrollee as a baseline health assessment tool.** HCFA’s Medicare+Choice regulations require that plans conduct “an initial assessment of each enrollee’s health care needs” within 90 days of enrollment.<sup>34</sup> Plans also must identify “individuals with complex or serious medical conditions,” assess those conditions, and implement appropriate treatment plans.<sup>35</sup>

All HMOs participating in the study mail a written health questionnaire to new enrollees. Health plan staff described these questionnaires as “wellness questionnaires,” “health risk assessment forms” or “written assessment tools.” These forms often are fill-in-the-bubble, multiple-choice types of surveys. Some plans use standard questionnaires, while others design their own questionnaires or modify standard forms. One plan Medicare director stated that a Social HMO had designed their tool.<sup>36</sup> Another plan uses a “modified PRA Plus,” a 17-question form developed at the University of Minnesota to screen for likelihood of hospital admission.

Yet reliance on a self-report questionnaire may not provide plans with sufficient baseline health information on all enrollees. Plans do not receive completed assessment forms for all enrollees. The return rates for the tool varied between plans, from a low of 30% to a high of 90%. It is not clear why this rate is so varied. Most plans make two or three follow-up efforts to obtain the completed questionnaire. Plans process the completed questionnaires differently. One HMO sends them to a contractor who collates the data and forwards them to the delegated medical groups. At another plan, a geriatrician reviews all survey forms.

Previous research has shown that elderly individuals at high risk for adverse health outcomes can be identified by self-reported health risk assessments.<sup>37</sup> However, some plan clinicians flagged

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<sup>32</sup> K. Maslow, *The CCN/AD Model* (Washington, DC: Alzheimer’s Association, July 1999).

<sup>33</sup> K. Maslow, *The HRSA/AoA Model* (Washington, DC: Alzheimer’s Association, July 1999).

<sup>34</sup> 42 CFR §422.112(a)(3)(v)(A).

<sup>35</sup> 42 CFR §422.112(a)(1)(iii)(B).

<sup>36</sup> Social HMOs are HCFA-selected demonstration projects in which the HMO provides prescription drugs, homemaker services, respite care, medical transportation, adult day health care and home health services in addition to the services ordinarily covered by Medicare HMOs. They may also provide expanded case management services. See W. Feldesman, *Dictionary of Eldercare Terminology* (Washington, DC: United Seniors Healthcare Cooperative, 1997).

<sup>37</sup> H. Fillit et al., “Opportunities for Improving Managed Care for Individuals with Dementia: Part 1—The Issues” *American Journal of Managed Care* (1999): 309-15; H. Fillit et al., “Opportunities for Improving Managed Care for Individuals with Dementia: Part 2—A Framework for Care” *American Journal of Managed Care* (1999): 317-24.

weaknesses in the questionnaires themselves. One medical director stated that the tool is “probably not reliable because the questions are convoluted,” but it’s an inexpensive way to do health assessments. A nurse in charge of case management pointed out that the form doesn’t indicate who completed it, thereby making it difficult for plans to fully evaluate the responses.

2. **Written health questionnaires may not yield information on whether an enrollee has possible dementia.** While self-reported health risk assessments may identify members at high risk for adverse health outcomes, it is difficult to ask individuals about their mental status through the mail.<sup>38</sup> Four HMOs in the study said that their instruments do not screen for dementia but do screen for some characteristics that may be associated with dementia, such as depression and restriction on activities of daily living. Two plan medical directors could not remember whether their tools screened for dementia, indicating not only their unfamiliarity with the instrument but also some unfamiliarity with screening for cognitive impairments. Other screening mechanisms may increase early detection of dementia. Telephone interviewing using the Mini Mental Status Exam may be a possibility, and one plan in the study indicated that they are considering using a telephone screening tool for cognitive status. Working with researchers the plan is piloting the telephone administration of this diagnostic tool.<sup>39</sup>
3. **HMOs in the study do not routinely screen Medicare beneficiaries for dementia.** Managed care plans have the potential to conduct population-wide screening to better manage the care of targeted populations. HCFA regulations recognize this opportunity and the need to take a comprehensive approach to caring for those with chronic, significant impairments. HCFA requires Medicare+Choice plans to identify “individuals with complex or serious medical conditions,” assess those conditions, and implement appropriate treatment plans. Some researchers and advocates have suggested that by instituting screening with brief mental status exams of people over a defined age, e.g. 75, those who may be impaired could be referred for diagnostic assessment and, ultimately, appropriate care.<sup>40</sup> HMOs in this study have not implemented population-wide dementia screening. The majority of these HMOs do not yet appear to have developed a strategy for early diagnosis and treatment.
4. **Primary care physicians have varying levels of expertise in geriatrics, generally and in dementia diagnosis and care, specifically.** The medical director of one Medicare+Choice plan, an internist, stated that “primary care physicians don’t know how to identify cognitive impairments. They lack knowledge about different types of dementia and how to diagnose them, and many think there is nothing to be done for dementia patients.” She put herself in the same category, stating that until recently she believed that different dementias were interchangeable. While most of the HMOs in the survey have some geriatricians on staff or in their provider networks, many do not have geriatricians available to serve as primary care physicians. The HMOs with the greatest number of geriatricians on staff or in their provider network in this study are affiliated with major teaching hospitals or located near medical schools offering geriatric fellowship programs.

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<sup>38</sup> Ibid.

<sup>39</sup> Correspondence with David Knopman, M.D., August 23, 1999.

<sup>40</sup> D. Cherry, “Dementia Services in Managed Care: Issues and Trends,” awaiting publication in *Generations, Journal of the American Society on Aging*.

5. **Some Medicare+Choice organizations are beginning to place a greater emphasis on dementia diagnosis and care.** Four of the eight plans in the study are initiating programs to improve protocols and delivery of services for geriatric patients. Interestingly, three of the four are nonprofit HMOs.<sup>41</sup> Some of these programs specifically focus on dementia, while others are part of broader efforts to better serve chronically ill, elderly members. These efforts include the following examples:
- One large HMO has initiated a model project for persons with dementia and their families in a major metropolitan area. It includes a guideline for the diagnosis and management of dementia, a provider training program, member education and support, and care coordination. The clinical practice guideline relies on the primary care physician to begin the diagnostic process with a history and the Folstein Mini Mental Status Examination. Further diagnostic work follows if needed, including laboratory tests, neuroimaging and neurologic, psychiatric or geriatric consultation. If dementia is diagnosed, the patient is referred to a care manager who works with the family and physician to develop a care plan. Provider education aims to teach physicians, nurse practitioners, physician assistants, and social workers to list the signs and symptoms of dementia, make a differential diagnosis, and appropriately manage the patient's course of illness. Care coordinators provide information, support and referral to caregivers, and facilitate adherence to the guidelines and care plan.
  - A large IPA-model HMO with about 18,000 Medicare+Choice members has a geriatric case management program for enrollees identified as "high risk" through the screening instrument. In addition, they have developed new treatment guidelines for dementia. The treatment guidelines, developed by neurologists, geriatricians and psychiatrists, include diagnostic testing and a step-by-step procedure for care. Primary care physicians do the diagnostic work-up, which includes the mini mental status exam, clock drawing test, and laboratory work. There are guidelines for prescribing donepezil (Aricept), a cholinesterase inhibitor drug used to treat Alzheimer's Disease. The plan has additional resources for members, caregivers and providers. Primary care physicians may refer patients to geriatricians or neurologists as needed for up to a year of unlimited visits.
  - A midwestern HMO delivers care to Medicare enrollees through 19 primary care clinics. At the clinic level they do a short-form mini mental status exam. Physicians, nurses, and social workers can refer patients to one of three outpatient geriatric assessment clinics. The comprehensive assessment evaluates the patient for dementia, depression, and nursing home placement, among other issues. A social worker makes a home visit, followed by a 90-minute clinic appointment for the patient and caregiver. At the appointment a nurse does screening tests for dementia, depression, nutrition, pharmacy, gait, vision, hearing, and caregiver stress. The team evaluates information and makes recommendations at a family conference and a social worker follows the patient. Primary care physicians perform follow-up.
  - A small Medicare+Choice organization, which has a large number of cognitively impaired members, has a Frail Older Adult Management Program. Referral to this program initially was based on whether a member had two hospitalizations in the previous year, but standards for

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<sup>41</sup> A recent study compared quality-of-care measures for investor-owned and not-for-profit HMOs. Compared with not-for-profit HMOs, investor owned plans had lower rates for the 14 quality-of-care indicators examined in the study. Researchers concluded that investor-owned HMOs deliver lower quality of care than not-for-profit plans. D. Himmelstein et al., "Quality of Care in Investor-Owned vs. Not-for-Profit HMOs," *Journal of the American Medical Association* (July 14, 1999): 159-163.

referral have since loosened. When a member is referred, a geriatric nurse practitioner does eight different assessments for dementia, depression, caregiver stress, and other health care issues. The nurse uses the mini mental status test and the clock drawing to identify cognitive impairment. She and a social worker follow the patients after evaluation. The HMO has considered the development of primary care geriatric clinics, but currently views them as too expensive. The health plan has new case management software that tracks the patient's history and allows clinicians to note "social/psych/nursing" issues, including a mini mental status exam score.

- 6. HMOs have case managers, but most don't provide care management over a sustained period for dementia patients.** This study asked HMOs whether they have case managers for elderly enrollees who have been identified as having cognitive impairments. All of the HMOs have case managers who at times may work with cognitively impaired enrollees. Yet, other than the HMO with a specific pilot project for dementia patients, none of the HMOs have case managers specifically for coordinating care of those patients.

Clinicians at one HMO discussed the difference between "case management" and "care management." Case managers focus on utilization of services; they may authorize services and do initial and concurrent reviews of care, usually from an office. Case management generally is crisis-oriented and episodic. As reported by several HMOs in the study, they may get involved in hospital discharge planning, transitional care, and skilled nursing facility (SNF) placement. Care management, on the other hand, is a process for tracking a patient over time, possibly for life, and is not limited by episodes of care or hospitalization. A care manager might be assigned to patients with certain specific diseases or conditions. In one plan's model, the care manager (a nurse practitioner) follows patients across sites of care, e.g. at home, in the hospital, at the physician's office, or in a long-term care setting. "One of the purposes of the process is to have accurate and complete information about the patient and to be able to share that information with all of the clinicians who come in contact with the patient so that appropriate decisions can be made—appropriate referring to quality of life and function as well as cost," explained the nurse practitioner. Only three of the plans in the study used a care management model for frail older adults, some of whom may have dementia. A fourth plan has a Chronic Care Project with some elements of care management, but has not yet extended the project to frail elders. Care management may have greater utility than case management for the long-term needs of cognitively impaired elders.

- 7. Medicare+Choice plans face challenges in continuing to care for enrollees with dementia once they enter a long-term care facility.** About 3 out of 10 people with Alzheimer's Disease live in long-term care facilities, and half of all nursing home patients have dementia.<sup>42</sup> Medicare only covers the costs of SNF care for a limited time period. Although most institutionalized beneficiaries with dementia receive custodial rather than skilled nursing care, they may continue to be enrolled in the health plan after entering a residential facility. While these institutionalized enrollees can continue to be followed by their primary care physician, several plans noted that some long-term care facilities require that residents be seen by in-house staff only. One HMO's Medicare director said that primary care physicians are supposed to follow patients in the nursing home, but don't generally do a good job. One plan noted that case managers only remain involved during the first 100 days of SNF care. The medical director for long-term care at a health plan with a geriatric case management program stated that he'd like to have the geriatric nurse practitioner and case managers take an active role with nursing home patients, such as participating in the nursing home's care planning process, but they lack resources to do so.

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<sup>42</sup> <http://www.alz.org/facts/rtdemen.htm>; <http://www.alz.org/facts/rtstats.htm>.



**M**r. C enrolled in Wheatfields Health Plan, an HMO, four years ago. Since then, his health has declined and recently he was diagnosed with Alzheimer's Disease. Mr. C has no health care proxy. Recently, he fell and broke his hip. After surgery and a five-day hospital stay, he was given a piece of paper by the hospital social worker saying that he will be discharged in two days. He can barely walk and has nobody to care for him at home.

### **c. Advance Directives and Surrogacy**

When Congress passed the Patient Self-Determination Act (PSDA)<sup>43</sup> in 1991, it recognized that Medicare and Medicaid beneficiaries may become incapable of making their own health care decisions and that facilities participating in those federal programs could play a vital role in informing and educating patients and families about advance planning for incapacity. The Act requires all Medicare HMOs to:

- develop written policies and procedures consistent with state law about health care decision-making rights;
- give individuals at the time of enrollment a summary of health care decision-making rights in the state, and a summary of the plan's policy concerning advance directives;
- inquire whether an enrollee has an advance directive and if so, document the fact in the medical record; and
- educate staff and community about advance directives.

By complying with the PSDA, plans can increase the likelihood that there will be an identified surrogate to participate in decision-making if an enrollee becomes cognitively impaired.

The role of such surrogates becomes vitally important in several contexts. Surrogates may make a broad spectrum of treatment decisions. Surrogates may receive critical information from the HMO, such as changes in premiums, benefits, and even plan terminations. When a Medicare+Choice organization decides to deny, reduce or terminate care or deny payment, a surrogate may be an appropriate person to receive notice of these organization determinations and to decide whether to file an appeal or grievance.

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<sup>43</sup> Omnibus Budget Reconciliation Act of 1990, Pub. L. 101-508, §§ 4206 & 4751 (Medicare and Medicaid, respectively) (codified at 42 U.S.C. §§1395cc(a)(1)(Q), 1395mm(c)(8), 1395cc(f), 1396a(a)(57), (58), 1396a(w)).

HCFA regulations explicitly require HMOs to give PSDA information to the family or surrogate of incapacitated enrollees.<sup>44</sup> However, the regulations lack specific guidance for Medicare+Choice organizations about providing notice of organization determinations and other plan information to surrogates, or about a surrogate's authority to pursue appeals and grievances on behalf of enrollees with cognitive impairments.<sup>45</sup>

- 1. HMOs provide information on advance directives at the time of enrollment.** Medicare+Choice plans in this study provide the advance directive information required by the Patient Self-Determination Act in written form. New member packets often include brochures about health care decision-making in general or specific types of advance directives such as living wills or health care proxies. Some utilize brochures published by state agencies such as the Attorney General's office, describing state health care decision-making law. Some health plans include advance directives information in the Evidence of Coverage. New member seminars may cover advance directives, and one plan has prerecorded advance directives information on its nurse advice telephone line. A geriatrician at another HMO gives presentations at senior centers and nursing homes on advance directives.

After enrollment, the dissemination of information on advance directives seems spotty. As one plan's medical director stated, "Providers don't know how to bring it up. It's on the bottom of the doctor's list." Another physician stated that during clinic visits, patients are given information but it is not systematic. It is on the "problem list" that doctors are supposed to cover, but the health plan has no way to verify whether the discussion occurs. One HMO has conducted workshops with physicians repeatedly, using role plays and a video to encourage discussions between doctor and patient on advance directives. Another HMO gives providers brochures on advance directives to place in their office waiting rooms. If a health plan has a specific geriatric assessment protocol, advance directives often arise during those assessments. The 90-minute screening appointment at one plan's geriatric assessment clinic includes a mandatory advance directives discussion. Since mildly demented patients may retain the capacity to make an advance directive, the assessment clinic may be a good locus for the discussion.

- 2. HMOs rely on physicians and medical groups to document that patients have advance directives.** Most HMOs in the study have no systematic way to record or disseminate information within the provider network about patients' advance directives. HMOs and providers need to be aware of patients' advance directives so they can identify surrogates and facilitate desired treatment options. When advance directives are documented only at providers' offices, HMOs may miss a critical opportunity to communicate about a patient's advance directive to all providers and facilities in the HMO. The failure to transmit information about a patient's advance directive when the patient moves from out-patient setting to hospital to nursing home has been noted as a widespread problem in the fee-for-service setting.<sup>46</sup> Many HMOs seem to share this difficulty. In most cases, the plan administration has no knowledge of an enrollee's advance directive since the information stays with the medical group. Conversely, one plan said that if a member sends the plan's administrative office a copy of an advance directive, plan personnel put it in a hard file and the information never gets to the medical group, hospital or nursing home.

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<sup>44</sup> 42 C.F.R. §422.128(b)(ii)(D).

<sup>45</sup> In a Program Memorandum dated July 22, 1997, HCFA indicates that guardians and agents under a health care proxy may file appeals "to the extent provided under state law."

<sup>46</sup> R.S. Morrison et al., "The Inaccessibility of Advance Directives on Transfer from Ambulatory to Acute Care Settings," *Journal of the American Medical Association* (August 9, 1995): 478.

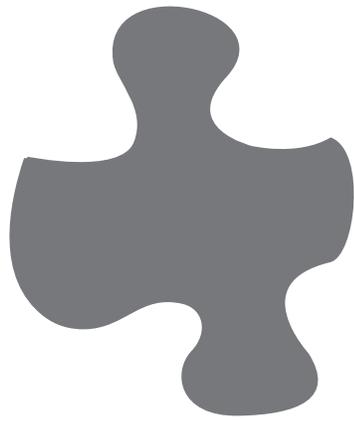
Two HMOs said they have widely accessible computerized patient charts. Both plans said that physicians could put documentation of advance directives in those computerized charts. At one of these health plans, a highly integrated system with a single medical group, the existence of the advance directive is accessible to all providers. The other HMO also has computerized medical records available that allow a clinician to note the advance directive in the care plan section of the chart. However, a geriatrician at one of these plans noted a weakness in the system, namely that there is no prompt to add advance directives information to the chart. He also noted that home care nurses and social workers are more cognizant of the need to document advance directives than doctors. At a third HMO, clinicians said that ideally an advance directive would be scanned into the chart, but expressed concerns about confidentiality.

- 3. Health plans lack procedures for sending correspondence, including notices of organization determinations, to enrollees and surrogates simultaneously.** Sending correspondence and legal notices both to the enrollee and the documented surrogate is optimal procedure, as the enrollees should participate in decision-making to the limits of their abilities. Their rights may be protected through practices that keep an appropriate surrogate informed while respecting the enrollee's own right to receive information. Yet as one plan's Medicare director explained, "The system is not set up well to deal with surrogacy." Several HMOs in the study said that notices go to the member unless an agent under a power of attorney provides documentation of authority and requests a change of address. In that case, the correspondence goes only to the surrogate. One plan said correspondence could only go to the member. Only one of the eight plans said that their system could send information to both the member and the surrogate simultaneously. The design and capacity of the plan's database or computer system seems in many cases to determine who receives information.
  
- 4. Most Medicare+Choice plans in the study stated that legal guardians and agents under a health care proxy can file an appeal of an organization determination.** According to a HCFA Program Memorandum, "A court appointed guardian or agent under a health care proxy to the extent provided by state law may file an appeal." Several plans incorporate this language in their member handbook or Evidence of Coverage. While impaired beneficiaries are well-served by this policy, several issues remain. First, as explained above, health plans may be unaware of the member's cognitive impairment or that the member has a guardian or agent, particularly if the member has become impaired after enrollment. In such a case, the surrogate will likely receive no notice of the plan's determination, and may be unaware of the need for an appeal or the existence of appeal rights. In addition, plans may not recognize that other surrogates are equally empowered by state law to file an appeal. If the state is one of over 30 with a health care consent statute, a relative or friend may be authorized to make health care decisions much like a health care proxy. If the plan is unfamiliar with the ramifications of a health care consent law, it may deny an appropriate surrogate a role in the appeal process.

Health plans also permit "authorized representatives" to participate in the grievance and appeal process.<sup>47</sup> This practice is of limited utility to beneficiaries with diminished capacity. To appoint a representative, one must retain the ability to understand what a determination and an appeal are, and to knowingly appoint someone to pursue the matter. Enrollees who are unable to fully understand a plan's decision and decide to seek recourse probably lack the capacity to authorize a representative in that situation.

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<sup>47</sup> "Authorized representative means an individual authorized by an enrollee to act on his or her behalf in obtaining an organization determination or in dealing with any of the levels of the appeal process...." 42 CFR §422.561.



# Conclusions

**W**hile this study gives a “snapshot” of how Medicare+Choice plans currently approach beneficiaries with dementia, further study is clearly required. Health plans, consumer advocates, professionals in the aging field, HCFA staff, and perhaps even federal and state legislators can work together to consider the complex interplay of law, medicine, and Medicare policy as they relate to Medicare beneficiaries with dementia. Medicare+Choice plans, beneficiary advocates, and policy-makers may want to consider the following questions:

**How can plans ensure that cognitively impaired beneficiaries have the protection of an appropriate surrogate participating in the enrollment decision?** This question requires further exploration and development. Medicare+Choice organizations should consider more extensive education for marketing and enrollment personnel on topics such as normal changes of aging, dementia, accommodations for potential enrollees with disabilities, and health care decision-making law. Health plans might consider designating a point person within the plan who has expertise on these topics, or a small team of such persons. Appropriate plan personnel could include geriatric nurse practitioners, social workers with experience in geriatrics, geriatricians, and elder law experts. Health plans could also develop a working relationship with aging network organizations such as area agencies on aging, senior centers, Alzheimer’s Association chapters, legal services providers and other providers working with the older population in the community. Health plans and community agencies could collaborate on delivering educational sessions for staff and community members.

**How can Medicare+Choice plans enhance the enrollment verification process?** Most Medicare HMOs seem to be using a telephone call verification process to check whether individuals who have signed election forms understand that they have chosen an HMO, and the rules and ramifications of such membership. This process appears to be a workable method to guard against enrollment of beneficiaries who lack the capacity to validly enroll in a Medicare+Choice plan. Several possible enhancements of the process might be considered:

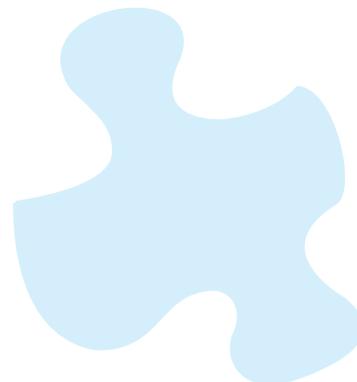
- Plans could call all beneficiaries who have filled out the election form, not just a fraction as some currently do.
- Rather than asking “yes” or “no” questions, plans might ask beneficiaries to explain how an HMO works in their own words. This might better evaluate their understanding.
- Plans could structure the enrollment process so that the actual enrollment does not occur until the verification call has been satisfactorily accomplished. In that case, there would be no need for disenrollment (retroactive or otherwise) if the call screened out someone who lacked capacity to make the enrollment decision. This procedure might require clarification or change of current HCFA policy. Health plans could work with HCFA policy staff toward that end.
- The verification call could include a few simple questions about advance directives and surrogates. This process would help HMOs fulfill their obligations under the Patient Self Determination Act, educate enrollees about their rights and opportunities to plan for incapacity, and help ensure that if the enrollee later became incapacitated, a surrogate could step in to make decisions on their behalf.

**How can plans help members to prepare for the possibility that they will develop dementia or become otherwise incapacitated in the future?** First, plans can take a more coordinated and comprehensive approach to meeting the requirements of the Patient Self-Determination Act. In addition to handing out brochures at the time of enrollment, plans can work more closely with providers, educating them about the importance of discussing health care decision-making and advance directives with their patients. They also could enhance documentation of existing advance directives by reminding providers to include the information in the patient's chart, instituting coordinated information systems so that the documentation is accessible to all providers and health care settings, and developing methods of conveying the information when members move from home to hospital to long-term care setting.

Medicare+Choice plans also might work with elder law experts, HCFA staff and others to develop a simplified advance directive that enrollees could execute at the time they enroll in the plan. This form could be a streamlined health care proxy, enabling an enrollee to designate a surrogate decision-maker who could work with the health plan and providers if the enrollee became unable to make decisions about plan membership, benefit choices, and health care services in the future. Many plans currently ask for an emergency contact person at the time of enrollment. Plans could go further by asking if there's someone the enrollee would like to designate to act on their behalf if needed in the future. Plans could follow-up by sending the enrollee the form with a simple explanation. Plans would need to ensure that such a form met the requirements of state health care decision-making law, and that enrollees received sufficient counseling to understand the significance of executing the document. If properly designed, such an instrument could clarify the proxy's authority to make enrollment and disenrollment decisions, file grievances and appeals, and make a full spectrum of health care decisions. It also should be clear that the grant of authority does not become effective until the enrollee loses decision-making capacity.

**How can Medicare+Choice plans ensure that both enrollees and surrogates receive all necessary correspondence and notification from the plan?** Most plans in the study lacked the technical capacity or system design to enable surrogates or designated family members/significant others to receive copies of notices. This deficiency is particularly significant if the plan sends organization determinations to incapacitated enrollees, thereby failing to give notice to anyone who can appeal on the enrollee's behalf. Plans could develop systems allowing dual notification, while protecting the privacy of enrollees who wish to be the sole point of contact with the plan. This system will require investigation both of the legal ramifications of dual notification and the technical systems needed for communication with all parties.

**How should health plans conduct baseline health assessments to promote early diagnosis and appropriate care for Medicare beneficiaries with dementia? Once such enrollees are identified, how can plans best utilize their resources to provide care for this population?** Medicare+Choice plans may want to consider whether population-wide screening, e.g. of all beneficiaries over a specified age, will yield better diagnosis and care management for enrollees with dementia. Plans could weigh considerations of efficiency, accuracy, sensitivity to enrollee needs and cost-effectiveness in developing a strategy for identifying cognitively impaired enrollees. Health plans can draw on the expertise of national groups such as the Alzheimer's Association as well as experts in geriatrics to answer these questions. The results of pilot projects such as those described in this report may assist plans in designing a delivery protocol.



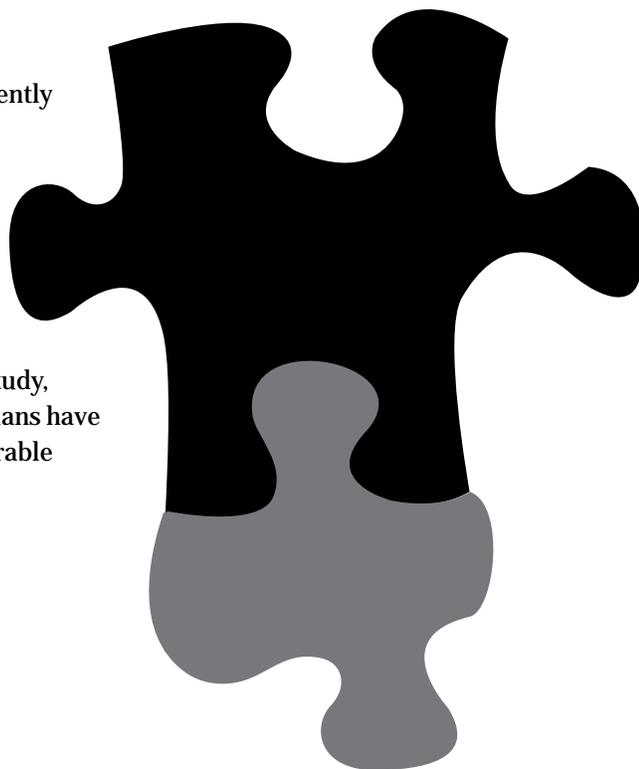
**How can HCFA enhance the ability of Medicare+Choice plans to appropriately identify and serve cognitively impaired Medicare beneficiaries?** HCFA could consider the following actions:

- HCFA Medicare+Choice manual and marketing guidelines could require that agent training include information on incapacity and state surrogate decision-making law;
- HCFA could require verification calls to ascertain whether beneficiaries have the capacity to contract with a Medicare+Choice plan;
- HCFA's regulations or manual could clarify that enrollment does not occur until the health plan has verified that the beneficiary had the capacity to make the decision to enroll. Alternatively, HCFA could state explicitly in the regulations and in the manual that retroactive disenrollment can be used for beneficiaries who have cognitive impairments and enrolled without understanding their own action;
- HCFA could clarify in its regulations that persons authorized by state law to make health care decisions for a beneficiary can enroll a beneficiary in a Medicare+Choice plan;
- HCFA could strengthen its regulations to ensure that identified surrogates as well as beneficiaries receive plan notices and information;
- HCFA could clarify that identified surrogates for incapacitated enrollees are parties to organization determinations, reconsiderations and grievances, and may assist enrollees in appeals and grievances.

HCFA can continue to work with health plans, consumer advocates and legal experts to ensure that the agency's policies maximize the rights of and services to cognitively impaired Medicare beneficiaries.

**Can changes in state and/or federal law enhance access to appropriate managed care for cognitively impaired older persons?** Existing law probably provides an adequate framework for an improved system of dementia care through the Medicare+Choice programs. Further study is needed to determine whether legislative reform can enhance the ability of surrogates to act on behalf of incapacitated Medicare beneficiaries.

While the nexus of Medicare managed care and dementia has only recently come under scrutiny, some health plans, practitioners and other experts have identified promising practices. These practices include training marketing agents and administrators on the issues and challenges facing persons with dementia; conducting population-based screening for dementia; developing protocols for serving members with dementia and their caregivers; and enhancing awareness about and documentation of advanced directives among plan personnel, providers, members, and caregivers. With continued study, experimentation and support from policy-makers, Medicare+Choice plans have the potential to improve services and deliver quality care to this vulnerable population.







**Back Cover**