

CHAPTER

7

**Shared decision making and its
implications for Medicare**

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Chapter summary

Medicare beneficiaries face certain challenges when making health care decisions. Although they are insured, on average, they are more likely to be poorer, less educated, cognitively impaired, faced with multiple chronic conditions, and less health literate than other consumers. All these factors may increase their difficulty understanding the information they receive about their health conditions and the risks and benefits posed by different treatments. In an effort to mitigate these problems and to make care more patient centered, some clinicians have adopted a model of shared decision making.

Shared decision making is the process by which a health care provider communicates personalized information to patients about the outcomes, probabilities, and scientific uncertainties of available treatment options, and patients communicate their values and the relative importance they place on benefits and harms. The goal of shared decision making is to improve patients' knowledge of their condition and give them a more realistic perception of treatment outcomes so that they can arrive at treatment decisions with their physicians that reflects their values and preferences. Information is conveyed through patient decision aids that provide patients with evidence-based, objective information on all treatment options for a given condition. Decision aids are generally used when the choice among treatment options depends heavily on patient assessment of risks and benefits. Some policymakers

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believe shared decision making has the potential to help diverse populations take an active role in managing their health.

Shared decision making must be distinguished from patient decision making. Physicians, not patients, have the expertise to know what approach to surgery is best, for example, or the side effect profile of different medications. Only patients know what their feelings are toward particular risks and benefits. When the patient understands the risks and the physician understands the patient's concerns, the physician is better able to recommend a treatment that will address the medical problem and respect the patient's values.

Effective shared decision-making programs require physician leadership and support, although physicians are not generally involved in daily operation of the programs. In fact, to enlist physician support, shared decision-making protocols must fit seamlessly into clinical practice and not increase the time physicians spend during appointments. To date, specialists have been more successful in implementing shared decision-making programs than primary care doctors because they are more likely to engage in shared decision making at a time when it is most useful to patients—before making a treatment decision on procedures like cancer treatment or back surgery. In contrast, patients may not invest the same amount of effort to understand the advantages and disadvantages of decisions like cancer screening options that they must make with their primary care physician.

Medicare beneficiaries have had limited experience with shared decision making. Some Medicare Advantage plans have begun implementing shared decision-making programs. Clinicians attempting to introduce shared decision making into traditional fee-for-service (FFS) Medicare face many challenges. Most physicians treating Medicare beneficiaries do not have the office infrastructure or functioning clinical information technology system to easily integrate these programs into their practice. In addition, the FFS payment structure does not compensate for this behavior.

Medicare could promote the use of shared decision making in a number of ways: design a demonstration project to test the use of shared decision making for Medicare beneficiaries, provide incentives to practitioners who adopt shared decision making, provide incentives to patients who engage in shared decision making, or require providers to use shared decision making for some services. These strategies are not mutually exclusive. Each has advantages and disadvantages. Policymakers would have to decide on the design and scope of the policy.

In future work, we will discuss some of the challenges Medicare faces trying to communicate with beneficiaries about how their health care services will be delivered and financed. Can the principles and techniques of shared decision making be used to help beneficiaries make choices about plans and providers as well?

The Patient Protection and Affordable Care Act of 2010 includes provisions to promote the development of shared decision making within Medicare and the health system in general. ■

Glossary

Health literacy: The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

Patient activation: A person's ability to self-manage his or her health and health care.

Patient decision aid: A tool that provides patients with evidence-based, objective information on all treatment options for a given condition. Decision aids present the risks and benefits of all options and help patients understand how likely it is that those benefits or harms will affect them. There are many kinds of decision

aids, including written material, web-based programs, videos, and multimedia programs.

Preference-sensitive care: Care that depends on patient preferences when two or more medically acceptable options exist.

Shared decision making: The process by which a health care provider communicates personalized information to patients about the outcomes, probabilities, and scientific uncertainties of available treatment options and patients communicate their values and the relative importance they place on benefits and harms. ■

Introduction

Like all health care consumers, Medicare beneficiaries have many decisions to make about the health care services they use and how those services will be delivered and financed. They also must decide where to go for care. Along with the information provided by their personal physicians and health plans, consumers receive multiple—and often conflicting—messages from the media, Internet sources, and advertisements from manufacturers of health care products.

In an effort to mitigate these problems and to make care more patient centered, some clinicians have adopted a model of shared decision making. Shared decision making is defined as an integrative process by which a health care provider gives patients necessary information about their clinical alternatives and patients have the opportunity to express their preferences.

Shared decision making must be distinguished from patient decision making. Physicians, not patients, have the expertise to know what approach to surgery is best, for example, or the side effect profile of different medications. Only patients know what their feelings are toward particular risks and benefits. For example, surgical treatment of prostate cancer may lead to impotence. Men will differ on the importance they attach to this harm compared with other results of treatment. Shared decision

making is designed to help patients clarify their values relative to the risks and benefits of different treatment options. When patients understand the risks and physicians understand patients' concerns, they are better able to come to a treatment decision that will address the medical problem and respect the patients' values (Kaplan et al. 2004).

To examine how shared decision making works in practice, the Commission conducted four site visits to institutions engaged in shared decision-making programs: Dartmouth Hitchcock Medical Center, Massachusetts General Hospital, Group Health Cooperative of Puget Sound, and Health Dialog, a company that provides shared decision-making services to health plans. Except for Health Dialog, the programs we examined are conducted in integrated delivery systems. We also conducted structured interviews with individuals implementing programs and companies that produce materials and services needed for shared decision making.

Roots of shared decision making

Many individuals must make medical decisions frequently, although they may have little knowledge of their conditions or the risks and benefits of different treatments. A University of Michigan survey found that in the past two years: 56 percent of respondents discussed with their

How did recent legislation affect shared decision making?

The Patient Protection and Affordable Care Act of 2010 adds Sec. 936, titled Program to Facilitate Shared Decision Making, to the Public Health Service Act. Under terms of the law, the Secretary is required to:

- contract with a consensus-based organization to develop and identify standards for patient decision aids, review patient decision aids, and develop a certification process for determining whether decision aids meet the standards;
- award grants or contracts to entities to develop, update, and produce patient decision aids; to test aids to ensure that they are balanced and evidence based; and to educate providers on their use;

- award grants to establish shared decision-making resource centers to develop and disseminate best practices to speed adoption and use of shared decision making; and
- award grants to providers to develop and implement shared decision-making techniques with patient decision aids.

In addition, the law establishes a Center for Medicare and Medicaid Innovation within CMS. The Center may test models that assist individuals in making health care choices by paying providers of services and suppliers for using patient decision support tools. ■

doctors starting or stopping medications for hypertension, hyperlipidemia, or depression; 72 percent discussed a screening test for cancer; and 16 percent discussed one of four operations. Clinical experts identified four or five facts a person should know, such as the common side effects of medications or surgery. Survey respondents were asked the “knowledge questions” related to their decision. For 8 of the 10 decisions, fewer than half of respondents could answer more than one knowledge question correctly (Couper 2009).

Communication between patients and their physicians is a crucial component of medical decision making, but physicians and patients may not always share all the pertinent information. The same University of Michigan survey found that, among patients who had discussed an intervention with their health care provider, the provider tended to emphasize the pros over the cons and frequently recommended getting more tests or treatment (Couper 2009). While providers tended to focus on the benefits of an intervention, patients were interested in both benefits and harms. Researchers surveyed patients and providers to assess their rankings of key facts and goals for 14 treatment decisions. When providers were asked to choose the top three things patients should know about chemotherapy and hormonal therapy for breast cancer, not one selected side effects or risks, whereas almost one-quarter of patients wanted to know about serious side effects. When patients and providers were asked to choose

their top three goals and concerns for the 14 treatment decisions, none of the conditions had the same items in the top three. Providers had a tendency to cluster on a few goals; for example, for breast cancer decisions, they focused on keeping the breast, living as long as possible, and looking natural without clothes, whereas patients were more diverse in their goals (Sepucha 2009).

The goal of shared decision making is to improve patients’ knowledge of their condition and give them a more realistic perception of treatment outcomes so that they can arrive at a treatment decision with their physicians that reflects their values and preferences. Shared decision making is generally used when choice among treatment options depends heavily on patient assessment of risks and benefits. However, it is clearly not appropriate for all medical decisions. It cannot be used in emergency situations. It also has limited utility when the medical evidence about a treatment recommendation is unambiguous. In the programs that we studied, a small, discrete set of conditions were identified as appropriate for shared decision making, although the conditions differed somewhat in different programs. Some of the most common conditions were breast cancer, lumbar spine disease, and knee osteoarthritis.

Much of the impetus for the development of shared decision-making programs has been to reduce unwarranted variation in “preference-sensitive” care—that is, care

that depends on patient preferences when two or more medically acceptable options exist. Researchers argue that widespread regional variation in rates for preference-sensitive procedures like hysterectomy is unwarranted if they do not correspond to a similar distribution in patient preferences. The goal is to ensure that these procedures are chosen by informed patients who value their possible benefits more than the potential harms (O'Connor et al. 2004).

Health literacy and shared decision-making tools

Commission-sponsored research shows that, contrary to commonly held assumptions that older people defer to their physicians, elderly patients are interested in participating in their health care treatment options (Gerteis et al. 2008). Yet other evidence shows that health literacy decreases and decision-making processes change with age (Finucane et al. 2002, Kutner et al. 2006). The drop in health literacy suggests that Medicare should explore alternative beneficiary education and communication strategies that take into account the cultural and learning style differences of the population.

Health literacy

Health literacy is defined by the Institute of Medicine as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Institute of Medicine 2004). Estimates quantifying limited health literacy find that nearly half the population has low or marginal health literacy (Paasche-Orlow et al. 2005).¹ Health literacy is lower for certain subgroups, including the elderly, racial minorities, and low-income adults (Kutner et al. 2006).

Statistical literacy is a component of health literacy and considerable evidence suggests that many adults fall short on basic levels. In one study, researchers found that in a nationally representative sample of adults aged 35 to 70, only 25 percent could convert 1 in 1,000 to 0.1 percent; 70 percent of the sample could convert 1 percent to 10 in 1,000; and roughly a quarter of the sample could correctly estimate how many times a coin would likely come up heads in 1,000 flips (Gigerenzer et al. 2008). It is not surprising that this difficulty understanding probabilities leads to confusion about the risks and benefits of health care procedures.

A review of experimental studies suggests that many patients do not understand the difference between statements about reduced risk expressed in relative terms and such statements expressed in absolute terms. They tend to evaluate a treatment alternative more positively if the benefits are expressed as a relative risk reduction (Covey 2007). To illustrate the difference between relative and absolute risk presentations, saying that “a cancer screening test every two years will reduce the chance of dying from that cancer by around one third over the next ten years” is a statement of relative risk reduction, whereas “a cancer screening test every two years will reduce your chance of dying from that cancer from around 3 in 1,000 to around 2 in 1,000” is a statement of absolute risk reduction (Gigerenzer et al. 2008). Generally, patients overestimate the benefits of screening procedures while underestimating the harms. They also confuse early detection with prevention and seek certainty from tests or treatments (Gigerenzer et al. 2008). This finding emphasizes the importance of carefully considering the optimal presentation of risk when educating patients and encouraging them to make informed decisions.

Health and statistical literacy levels affect how individuals gather health information. In one study, adults with high levels of health literacy got most of their information on health issues from written sources such as newspapers, magazines, brochures, and the Internet. Adults with low health literacy got most of their information on health issues from radio and television (Kutner et al. 2006).

Low health literacy is associated with poor health outcomes, controlling for demographic and socioeconomic factors, including income. Researchers found that elderly adults with inadequate health literacy were more likely to be in poor physical and mental health (Wolf et al. 2005). Low levels of health literacy were associated with worsened diabetes outcomes, fewer self-management behaviors, and decreased knowledge about one's chronic disease (Cavanaugh et al. 2008, Gazmararian et al. 2003, Schillinger et al. 2002). Among elderly managed care enrollees, those with lower health literacy were also less likely to receive preventive services, such as influenza vaccines and mammograms. For this group, inadequate health literacy was a risk factor for hospitalization (Baker et al. 1998, Baker et al. 2002). Finally, one study found that low health literacy was one factor contributing to racial disparities in the rates of preventive services among the elderly (Bennett et al. 2009).

Tools to improve doctor–patient communication

Low health literacy among Medicare beneficiaries argues for the use of tools such as patient activation, decision aids, and health information technology (IT) as a way to improve communication between doctors and patients.

Patient activation

Researchers find that patient activation—a person’s ability to self-manage his or her health and health care—is positively associated with health care outcomes (Remmers et al. 2009). Someone with high patient activation is more likely to receive preventive care and engage in preventive health behaviors, such as seeking relevant information on their health condition, implementing lifestyle changes, adhering to treatment plans, and asking questions about their health care (Seubert 2009).

Some research suggests that high patient activation may help mediate the adverse effects of low health literacy. One study tested patient comprehension and ability to choose the best hospital based on hypothetical quality information. Researchers found that survey respondents with low health literacy and high activation had better comprehension and made better choices than their low-literacy and low-activation counterparts. For example, given hypothetical quality information about a few hospitals, respondents scoring poorly on literacy and activation made the high-quality choice slightly more than half the time. However, respondents scoring poorly on literacy and well on activation made the high-quality choice roughly 70 percent of the time (Hibbard et al. 2007, Seubert 2009). Additionally, increasing patient activation may help address racial and ethnic disparities because social–environmental factors are associated with activation and, in turn, activation is correlated with healthy behaviors and positive health outcomes. Researchers modeled racial parity in patient activation levels and predicted health outcomes that substantially narrowed the disparities (Hibbard et al. 2008). These findings indicate that improving patient activation may improve decision making among patients.

Decision aids

Patient decision aids are an essential element of shared decision making. They are tools that provide patients with evidence-based, objective information on all treatment options for a given condition. They present the risks and benefits of all options and help patients understand how likely it is that those benefits or harms will affect them.

Patients are asked to weigh their personal attitudes toward those risks and benefits and take an active role in the treatment choice. By helping patients to identify their concerns, the decision aid helps them formulate questions to discuss with their physicians.

In recent years, decision aids have proliferated. One recent compendium found more than 500 decision aids, including 200 that meet minimum quality standards (Ottawa Hospital Research Institute 2009).² Developers include the Agency for Healthcare Research and Quality; the National Cancer Institute; Healthwise, a nonprofit organization that produces patient education content for health plan web sites; the Foundation for Informed Decision Making; and the Mayo Clinic. In addition, many pharmaceutical companies and manufacturers of other products advertise discussion guides for patients to take to their physician appointments; these guides may not meet standards for objectivity.

To produce an effective decision aid, developers need two kinds of expertise. They must understand complex medical conditions and treatments and keep current with changes in the evidence base. They must also have the ability to translate this information into everyday language comprehensible to people with no medical training. The aids they develop must provide for patients to express their values and preferences. A substantial number of medical experts and communication specialists may be needed to develop and maintain multiple decision aids.

In 2003, the International Patient Decision Aids Standards Collaboration—a group of researchers, practitioners, patients, and policymakers from 14 countries—established a process to develop quality criteria for patient decision aids (Elwyn et al. 2006). The resulting framework called for evaluating decision aids on the basis of content, presentation, and effectiveness. The collaboration also developed a checklist that decision aid developers and evaluators can use to test whether the decision aid meets the criteria. The Patient Protection and Affordable Care Act of 2010 authorizes the Secretary to contract with a consensus-based standards-setting organization to develop quality metrics for decision aids used in shared decision-making programs and to develop a certification process to determine whether decision aids meet the standards (see text box, p. 196).

Health IT

Health IT facilitates the use of shared decision making. At both Dartmouth Hitchcock Medical Center and

Massachusetts General, program organizers use IT to track patients who could benefit from specific decision aids; allow physicians to order aids by clicking a button on the patient's medical record; disseminate aids; and, at times, track patient survey responses. Evidence suggests that an IT infrastructure may be critical to success.

Ideally, and at some places we visited, a physician can initiate the shared decision-making process with one click of a button. The technology already exists to incorporate standardized access to patient-specific educational resources into an electronic medical record system. As a result of the American Recovery and Reinvestment Act of 2009, CMS will implement Medicare and Medicaid payment incentives to providers, totaling an estimated \$36 billion over the next six years to encourage the adoption and use of certified electronic health record technology by hospitals and physicians (Blumenthal 2010, Congressional Budget Office 2009). Including provisions for access to patient-specific educational resources in common primary languages would streamline the shared decision-making process during a patient visit and facilitate the infrastructure for broader implementation of shared decision making.

Adoption and evaluation of shared decision-making programs

Shared decision-making programs continue to expand, but the challenges to broader dissemination remain significant. Initially, shared decision-making programs were established at academic medical centers. More recently, demonstration programs have been implemented at community-based clinics. For example, the Foundation for Informed Medical Decision Making currently sponsors demonstrations at 13 primary care clinics and 8 specialty care practices (Foundation for Informed Medical Decision Making 2010). In addition, some health plans provide shared decision-making services to their enrollees.

While evaluation of shared decision-making programs as a whole is still in a formative stage, the International Cochrane Collaboration has analyzed 55 randomized controlled trials of shared decision making with patient decision aids relating to 23 different medical decisions. Studies generally relate to preference-sensitive surgical decisions and testing or screening decisions. The studies have consistently shown that decision aids used along with counseling increase patients' knowledge, give them a more realistic perception of treatment outcomes, reduce the

proportion of patients who are passive in decision making, and improve agreement between patients' values and the options they choose. In general, the studies also showed a reduction in more invasive treatment options without adverse effects on health outcomes (O'Connor et al. 2004, O'Connor et al. 2009).

Although supporters of shared decision making emphasize its role in improving the quality of patient care, others believe it also has the ability to lower medical costs. However, data on cost savings are inconclusive. Although patients may choose less-invasive options, these treatments are not always less expensive than other options.

Adoption of shared decision making has been particularly high at breast cancer centers. Currently, about 50 centers are actively distributing decision aids as part of shared decision-making programs. One innovative program has been implemented at the University of California, San Francisco, breast cancer center. Premedical students distribute decision aids before physician visits and provide question listings, audio recordings, and note-taking services to help patients prepare for, participate in, and remember their visits (Belkora 2010, Foundation for Informed Medical Decision Making 2010).

One issue that could limit future adoption of shared decision-making programs is the lack of payment incentives. Physicians at Dartmouth Hitchcock Medical Center and Massachusetts General mentioned that shared decision-making programs in their institutions were implemented despite the negative incentives created by a fee-for-service (FFS) payment system. For example, surgeons can expect to see fewer patients electing back surgery if they engage in shared decision making. Specialists at Dartmouth Hitchcock Medical Center did not consider that a problem but believed a different payment structure would facilitate wider dissemination of these programs.

A number of states are promoting shared decision-making initiatives. In May 2007, Washington became the first state to enact legislation on shared decision making. The legislature directed the state Health Care Authority to enact a demonstration project at one or more multispecialty group practice sites providing state-purchased care. These sites must incorporate decision aids into areas of preference-sensitive care and evaluate the aids' impact. The ongoing demonstration project is based at Group Health Cooperative of Puget Sound. Group Health has been implementing a program for 12

preference-sensitive conditions related to elective surgical procedures.³

The law also includes legal protections for physicians who engage in shared decision making with their patients. Current standards of informed consent are ambiguous and vary by state. Thus, a physician applying evidence-based medicine may still be vulnerable to lawsuits (King and Moulton 2006). Under the terms of the law, if a patient or his or her representative signs an acknowledgment of shared decision making, that document serves as prima facie evidence that the patient gave informed consent to the treatment. Plaintiffs would face a high burden of proof to argue otherwise. A number of other states are considering similar statutes.⁴

Although failure to obtain informed consent is not the primary cause of many malpractice suits, some legal scholars have argued that poor risk communication in the informed consent process is an underlying factor in much litigation. For example, a patient may not understand the risks that a treatment entails (despite signing an informed consent form) and then sue when harms result from the procedure (Sharpe and Faden 1998).

To evaluate the demonstration project, Group Health will track the following outcomes:

- decision aid viewing
- patient satisfaction with decision aids
- procedure rates
- overall health care use of patients (number of physician visits, hospitalizations, medications)
- cost of program implementation and delivery
- impact of program implementation on providers and staff

Group Health began implementing the program January 2009. Implementation proceeded slowly. Organizers spent more than a year talking to physicians about shared decision making, trying to convince them to adopt it in their practices. They found that adoption rates of shared decision making varied among specialties, with orthopedists most receptive to the program.

Group Health recently provided some preliminary results. Over the past year, 3,200 decision aids have been distributed to patients, most ordered by their physicians.

Patients have reported a high degree of satisfaction and six of nine orthopedists also expressed satisfaction. (Two orthopedists were neutral and one was negative.) Physicians found no change in the amount of time they spent with patients, although some reported that the quality of the visit was better (Arterburn 2010).

More recently, Maine and Vermont passed legislation to study the feasibility of incorporating shared decision making within clinical practice. Other states considering initiatives include Florida, Connecticut, Minnesota, California, Oklahoma, and Massachusetts. In proposed legislation, Minnesota would require clinicians treating state-insured employees and Medicaid recipients to use shared decision making to receive payment for certain procedures, including chronic back pain, early-stage breast cancer, and benign prostatic hyperplasia (Kuehn 2009). Some initiatives (e.g., in Maine and Minnesota) include collaborations between the state and private employers to test shared decision making as an element in broader health delivery system reform.

Lessons learned to date on physicians' use of shared decision making

Effective shared decision-making programs require physician leadership and support, although physicians are not generally involved in the daily operation of programs. In fact, to enlist physician support, shared decision-making protocols must fit seamlessly into clinical practice and not increase the time physicians spend during appointments. In well-designed programs, patient appointment times remain the same but the conversation differs.

Optimal conditions for physicians' use

Studies have shown that physicians generally support the concept of better informed patients and have a positive attitude toward shared decision making but have not implemented its use in their practices. For example, most orthopedic surgeons responding to a 2004 member survey of the American Academy of Hip and Knee Surgeons said that shared decision making was a good or excellent idea. The most important benefit of decision aids used in the programs was increased patient comprehension. The major barrier they reported was that it would interfere with office work (Weinstein et al. 2007). Similarly, in a recent national survey of primary care physicians, 93 percent reported that

shared decision making sounded like a positive process. Nearly all said they would use patient decision aids if they met physicians' standards. They named lack of time with patients as the most important barrier to engaging in shared decision making (Foundation for Informed Medical Decision Making 2009b). Our site visits suggest key principles for obtaining physician participation in shared decision making.

- **Programs require physician support.** At both Dartmouth Hitchcock Medical Center and Massachusetts General Hospital, organizers stressed the importance of having physician support before trying to implement a shared decision-making program. Unlike the disease management programs we have examined in the past, physicians in these practices have taken the lead in shaping their institutions' use of shared decision making. In the programs developed at Massachusetts General, they are responsible for prescribing patient decision aids. At Dartmouth Hitchcock Medical Center, decision aids are prescribed automatically in a program designed by physicians. At both sites, physicians have the opportunity to review the material and they know that each decision aid is updated frequently by their peers.

Organizers of a demonstration project at Group Health of Puget Sound (see above) spent months informing physicians about the program and addressing their concerns before implementing a shared decision-making demonstration. They found that physician receptivity was not uniform. As at other sites we visited, physician response differed by specialty. One interviewee found more positive reactions from individuals in high-volume specialties. For example, orthopedists—a high-volume specialty—were more likely to appreciate shared decision making because it resulted in fewer patients who were poor candidates for back surgery or knee replacement. Additionally, they said that patients had more realistic expectations about treatment results.

Physicians may differ in their use of specific decision aids. In at least one case, a decision aid on colon cancer screening was not used initially at Dartmouth Hitchcock Medical Center. The institution's gastroenterologists were concerned that the aid might bias patients against screening because it presented not getting screened as a valid option. As a result, a small randomized trial was done that showed patients

chose screening at the same rate after watching the version that included one expert describing his decision, as a patient, not to be screened compared with a revised version that deleted his commentary. On the basis of these results, this decision aid is now in use at Dartmouth Hitchcock. Gastroenterologists at Massachusetts General did not object to use of this decision aid.

- **Programs are designed to fit into the way physicians practice.** Although most early programs resulted from physician initiatives, physicians are typically not involved in the program's day-to-day operation. At the sites we visited, program organizers took a team-based approach to shared decision making. Nurses, social workers, and others provided materials, counseling, and other assistance to patients to prepare them for their physician visits. The directors of the Center for Informed Choice and the Center for Shared Decision Making at Dartmouth Hitchcock Medical Center emphasized that these programs could work only if they fit into the way physicians practiced. If the program created more work for physicians or interrupted the work flow in the office, shared decision making was unlikely to be widely adopted. The Dartmouth Hitchcock Medical Center shared decision-making program is part of a comprehensive, coordinated care system for newly diagnosed breast cancer patients. It requires no additional work for the surgeons. Patients are automatically prescribed video-based decision aids upon diagnosis and asked to complete a survey after viewing the aid. Counselors are available to help patients with the material as well as other issues. When the surgeon sees the patient, she has the survey results indicating the patient's values and preferences as well as measures of how well the patient understood the information covered in the decision aid. Further aids are available to help patients decide about reconstructive surgery (Collins 2009).

The importance of designing systems that accommodate practice styles also was illustrated during our visit to Massachusetts General. Decision aids were disseminated to patients from two different primary care practices affiliated with the hospital. In each case, physicians received a list of the relevant materials they could prescribe to their patients. The list was incorporated into the patients' electronic medical record. Doctors could click on the ones they wanted their patient to receive and a department in the

hospital would mail them directly to the patient. This procedure worked in one practice but not in the other. Organizers discovered that in the second practice, physicians were accustomed to sending patients to a hospital patient library to obtain relevant information. They reorganized their system so that the list of decision aids was added to the other materials patients received in the library. As a result, physician use of the aids in the second practice increased.

- ***Programs have more impact when a feedback loop ensures that physicians meet with patients after they have seen decision aids.*** Primary care physicians at Dartmouth Hitchcock Medical Center described two models of shared decision making for the cancer screening programs they tested. In one case, all eligible patients were sent the decision aids before their scheduled preventive care visit. In the other case, patients received the aids when they arrived for their appointment. Evaluators concurred that the second model was less successful. To act on the information they received during their visit, patients would have to follow up with their physicians, although they may have had no further appointment scheduled. Ongoing demonstrations in a number of primary care clinics are testing the most effective way to deliver decision aids to patients at a time when they are likely to act on the information they receive.

Distinctions between specialty and primary care in use of shared decision making

Researchers stress the importance of implementing shared decision-making programs in primary care, and physician associations like the American Academy of Family Physicians have endorsed the model. However, intrinsic differences between primary and specialty care highlight the danger of assuming the broad applicability of shared decision-making programs without adaptations.

- ***Specialists are more likely to have a limited number of decision aids to prescribe for their patients.*** For example, breast cancer surgeons prescribe a decision aid that helps patients decide about lumpectomy or mastectomy for early-stage breast cancer. Primary care physicians deal with a wider range of issues. Organizers at Massachusetts General identify 22 decision aids that are available for use by primary care physicians. Programs include decisions about cancer screening, diabetes, heart disease, depression, end-of-life care, and general health. Primary care

physicians are less likely to know before a patient visit which decision aids may be appropriate. Many of the decisions they discuss with their patients are about strategies to diagnose patient symptoms rather than treatment options. At Massachusetts General, the most prescribed programs are aids about PSA testing, colon cancer screening options, advanced directives, and chronic lower back pain.

- ***Patients may find decision aids provided by specialists more salient than those provided in primary care practices.*** Specialists prescribe decision aids at a time when the information is most useful to patients—before meeting with the physician to decide on a procedure like cancer treatment or back surgery. The physician can then spend more time with the patient answering questions and discussing the options and less time explaining the basics of the diagnosis and treatment options. In contrast, patients may not be willing to invest the same amount of time to understand the advantages and disadvantages of different cancer screening options that they may receive from their primary care physician.
- ***In specialty care programs, physicians are more likely to receive the results of their patients' response to the decision aid.*** In the Dartmouth Hitchcock Medical Center breast cancer program, patients are not only surveyed about their values and preferences after using the decision aid, they are also asked questions to test their knowledge of the material they have viewed. Physicians receive copies of these surveys before the patient's appointment. They can assess patient values and preferences and also whether those preferences are based on an understanding of the decision trade-offs. In the primary care setting, patients may not have another appointment to see their physicians soon after they receive a decision aid, which may limit the utility of the decision aid.

Despite these difficulties, many proponents of shared decision making emphasize the importance of implementing the model in primary care settings before decisions about tests and treatments are made. For example, patients who are referred to surgeons are likely to choose surgery. If they discussed their treatment options with their primary care physician, they might choose other options like medical management, watchful waiting, or physical therapy depending on the condition.

Use of shared decision making for certain populations

The Commission has expressed considerable interest in the application of shared decision making to elderly, minority, and low-income patients. Conceptually, shared decision making represents an opportunity to improve knowledge and informed consent among groups that may have lower health literacy—including the elderly, racial and ethnic minorities, and low-income adults. To compensate for low levels of health literacy, some decision aids are consciously crafted at a fifth-grade reading level. Risks are presented in absolute terms instead of relative terms. Some decision aids are translated into Spanish and will soon be translated into other languages to apply to patient populations who may not speak English at home.

Despite efforts to make decision aids useful to vulnerable populations, the empirical evidence on shared decision making within minority and low-income populations is limited. Many sites implementing shared decision making programs do not have diverse populations or do not track results by demographic characteristics. For example, Group Health Cooperative of Puget Sound in Seattle does not record the race of patients who access decision aids through their personal health records. Dartmouth Hitchcock Medical Center serves a population that is fairly homogeneous racially but diverse socioeconomically, ranging from patients affiliated with Dartmouth University to rural patients for whom Dartmouth Hitchcock Medical Center is the only source of care. The Dartmouth Hitchcock Medical Center breast cancer program records the results of its patients' knowledge and preferences survey but has not analyzed the results by socioeconomic status.

The commercial sector has made somewhat more progress targeting shared decision making to minority and low-income populations. For example, Health Dialog, the for-profit company contracting with health plans to market shared decision making as a component of a health coaching service, uses demographic data to target its patient outreach by classifying patients in 60 population segments. Health Dialog uses a combination of demographic data (race/ethnicity, census ZIP code-level income, age, and family structure) and clinical data to identify which population segment a patient belongs to. Once that determination has been made, colors, photos, and taglines of the marketing material are adjusted to optimize outreach success. The head of the Consumer Segmentation and Engagement Strategies group told

us that they vary taglines on mailed outreach materials to resonate with different population segments, such as cost sensitivity, empowerment, and convenience. They adjust photos to depict members of the targeted patient's population segment. They also change color themes based on the results of extensive focus group testing that suggest that different populations respond differently to earth tones versus bright colors. Currently, these demographic targeting strategies aim only to increase participation in the health coaching service and not to influence the content of health coaching or shared decision-making materials. Measuring the success of this outreach targeting is difficult because most health plans that are Health Dialog clients do not collect race/ethnicity data on health coaching participation, much less share it with researchers. While efforts to date concentrate on encouraging participation, Health Dialog plans to implement population-specific content in 2010, including outreach aimed to lower dietary salt intake among African American and Hispanic populations (Costello 2009).

Improving outreach through targeting answers only part of the Commission's question about how shared decision making applies to vulnerable populations. There is still a dearth of information on the application and challenges of shared decision making among racial and ethnic minorities, low-income populations, and low health literacy populations, but promising initiatives are under way:

- ***Developing and testing educational materials to improve decision making for patients with advanced chronic kidney disease (CKD).*** A group of researchers at Johns Hopkins University School of Medicine is developing and testing educational materials to improve decision making for patients with advanced CKD, a condition that disproportionately affects African Americans. As patient decisions about treatments for end-stage renal disease (ESRD) are preference sensitive, these audiovisual and computer-based educational resources are designed to enhance shared decision making with regard to the choice of ESRD treatment. Researchers are working toward decision aids to assist incident ESRD patients and their families make informed decisions about live kidney donation and transplantation. To date, they have conducted focus groups with African American CKD patients and their family members. These groups have discussed the level of baseline understanding about treatment options, perceptions of advantages and disadvantages for each treatment choice, important elements of the patient experiences relative

to treatment choice, and the degree to which patients feel informed about insurance coverage for kidney transplantation (Foundation for Informed Medical Decision Making 2009a).

- **Testing an intervention to improve activation among patients in the waiting room of a community health center.** Researchers from City College in New York are implementing and testing interventions to boost patient activation among patients at a community health center with a diverse and low-income population. Project staff will test three strategies to assess their impact on patient activation scores compared with a control group. One group of patients will receive an intervention designed to help patients develop their question-asking skills and link those skills to health care decision making; a second group will view the video-based patient decision aid—Getting the Healthcare That’s Right for You—designed to make individuals more aware of how to be active participants in their care; a third group will be exposed to both interventions. These interventions will take place in the waiting room. The study will measure patient activation before and after the intervention (Gold 2010).
- **Impact of health literacy on outcomes and effectiveness of shared decision-making programs in patients with chronic diseases.** Recognizing that low health literacy may present an additional challenge in the management of chronic disease, researchers at the University of Cincinnati are implementing and testing the booklet and video version of a shared decision-making program for patients with coronary artery disease. Researchers will measure the effect of the video versus the booklet intervention on knowledge scores to assess whether the resulting difference is most pronounced for patients with low health literacy. Additionally, they will record relevant clinical outcomes six months after the intervention to assess whether patients with low health literacy became more or less involved in the management of their disease than their more literate counterparts (Foundation for Informed Medical Decision Making 2009a).

Shared decision making in Medicare

Medicare beneficiaries have had limited experience with shared decision making. Some health plans contract with

Health Dialog to provide shared decision-making services to their enrollees, including Medicare beneficiaries. In addition, some Medicare Advantage plans have begun implementing shared decision-making programs. One approach involves plans contracting with individuals serving as coaches to contact selected enrollees to discuss medical decisions as well as more traditional disease management services. Our interviews with nurse coaches and a health plan program coordinator suggest that Medicare beneficiaries are very receptive to their services. However, because they generally rely on claims data, the programs have difficulty identifying and contacting beneficiaries in time to prepare them to make a preference-sensitive decision.

Medicare could promote the use of shared decision making in a number of ways:

- Design a demonstration project to test the use of shared decision making for Medicare beneficiaries,
- Provide incentives to practitioners who adopt shared decision making,
- Provide incentives to patients who engage in shared decision making, and
- Require providers to use shared decision making for some preference-sensitive services.

These strategies are not mutually exclusive. Each has advantages and disadvantages. Policymakers would have to decide on the design and scope of any policy choice.

Medicare demonstration project

Clinicians attempting to introduce shared decision making into FFS Medicare face many challenges. Most physicians treating Medicare beneficiaries do not have the office infrastructure or functioning clinical IT system to easily integrate these programs into their practice. As mentioned earlier, incentives in the FFS payment structure do not compensate this behavior. However, the Commission has discussed two health system delivery initiatives in Medicare that have the structure and incentives to engage in shared decision making: medical homes and accountable care organizations (ACOs). CMS could initiate a shared decision-making demonstration project based on one of these delivery system models.

Medical homes

A medical home is a delivery system innovation designed to coordinate a patient’s health care through a central

clinical contact. In our June 2008 report, the Commission recommended that the Congress initiate a medical home pilot project in Medicare. We noted that eligible medical homes must meet stringent criteria, including at least the following capabilities:

- furnish primary care (including coordinating appropriate preventive, maintenance, and acute health services)
- use health IT for active clinical decision support
- conduct care management
- maintain 24-hour patient communication and rapid access
- keep up-to-date records of patients' advance directives
- be accredited/certified from an external accrediting body

Medical homes that meet these criteria have the infrastructure and the incentive to engage in shared decision making. A number of recent commentators have noted that shared decision making in primary care is a key element of patient-centered medical care (Berwick 2009, Mirabito and Berry 2010).

Accountable care organizations

ACOs represent another delivery system structure that has the potential to develop shared decision-making programs. The Commission and others have discussed the potential of ACOs, a set of providers who are responsible for the health care of a population of Medicare beneficiaries (Congressional Budget Office 2008, Fisher et al. 2009, Medicare Payment Advisory Commission 2008). Under an ACO structure, a group of physicians is teamed with a hospital that is given joint responsibility for the quality and cost of care provided to a large group of patients. By making providers jointly responsible for the quality of care and cost of a population, ACOs are designed to improve the coordination of care and reduce duplication of services. Because ACOs would take responsibility for resource use, Medicare could constrain spending for its beneficiaries with a system of withholds and bonuses. Such a system is intended to counterbalance the incentives in the FFS system to increase volume.

ACOs would have the financial incentive and the infrastructure to implement shared decision making. Because ACOs include physicians with multiple specialties, they would be best positioned to incorporate

shared decision making for preference-sensitive conditions as determined by the physicians within the practice.

Medicare could initiate demonstration projects in medical homes or ACOs to test the feasibility of shared decision making with the Medicare population. There are advantages and disadvantages to this approach. These organizations would have the infrastructure to implement shared decision making. They would need physicians within their organization who were willing adopters of the process. However, as these demonstrations introduce many innovations in the delivery system, Medicare might not want to include shared decision making as an additional element in the medical home or ACO model. As in other primary care settings, shared decision making in medical homes could be difficult.

Provide incentives to practitioners who use shared decision making

Some policy analysts have suggested that Medicare and other health care payers could provide incentives to physicians and other practitioners to use shared decision making with their patients. Incentives could be structured in a variety of ways, from allowing physicians to bill for shared decision making through the Medicare fee schedule to offering rewards or bonuses to physicians who distribute patient decision aids. Each strategy has advantages and disadvantages.

- The Medicare fee schedule includes add-on codes to evaluation and management visits that physicians can bill for prolonged visits when medically necessary. These time-based codes can be used only when more than half the duration of the visit is spent on counseling. Documentation must include a time estimate and a brief description of what condition and treatments were discussed. Time is measured by direct face-to-face contact between the physician and the patient. The codes are most often used by surgeons, oncologists, nephrologists, and other specialists (*Part B News* 2010a, *Part B News* 2010b). CMS could specify that these codes can be used by physicians who engage in shared decision making.

This approach has advantages and disadvantages. It could provide an incentive for physicians within FFS Medicare to engage in shared decision making. CMS would have to provide guidance on the criteria needed to document that shared decision making took place because use of this code could lead to increased Medicare spending. CMS would also need metrics to

evaluate the outcome of shared decision making in this setting.

- Criteria used to determine eligibility for pay-for-performance bonuses could include distributing relevant decision aids to patients. Wennberg and colleagues suggest that most performance incentives are designed to encourage the provision of more services (Wennberg et al. 2007). Bonuses for shared decision making would be one of the few performance incentives that could result in fewer services being performed over the course of an episode of care. After consideration of the risks and benefits of a treatment, a beneficiary may decide not to receive a service that otherwise would have been provided.

At least two private insurers have included documented use of shared decision making as a requirement for certain recognition or incentive programs. Blue Cross Blue Shield requires facilities seeking a designation as a Blue Distinction Center for knee and hip replacement or spinal surgery to offer shared decision making and preoperative patient education (BlueCross BlueShield Association 2010). A program called MedEncentive provides incentives to patients and physicians to use patient decision aids (Greene 2008).

For Medicare to use this approach, CMS would have to define criteria to ensure that shared decision making met quality criteria. For example, it would need to verify that patient decision aids were objective, evidence based, and up to date. It would also need metrics to evaluate the effects of the strategy.

Provide incentives to patients to engage in shared decision making

Incentives for patients may also facilitate the use of shared decision making by encouraging the use of decision aids and improving patient activation. A challenge for any incentive system targeting Medicare beneficiaries is tailoring it to the benefit structure and supplemental insurance patterns.

- Patient incentives may be effective among elderly, low-income, and diverse populations. Researchers at the University of California, Los Angeles, tested the effect of a small financial incentive on the likelihood that seniors at two community senior centers would attend screenings of videos about managing chronic diseases. One senior center served a low-income, predominantly African American community and the

other served a diverse middle-income community. Researchers found the highest rate of participation occurred among seniors receiving a \$50 gift card to attend three of the five screenings. These participants differed from their counterparts on some demographic characteristics (somewhat younger, more likely to be female, moderately more likely to be African American, moderately more likely to have lower household incomes) but not others (number of chronic conditions, baseline patient activation scores). Seniors who attended three or more screenings reported somewhat more physical activity postintervention and had significantly higher patient activation scores, both immediately after the intervention and six months later (Foundation for Informed Medical Decision Making 2009a).

- Patient incentives would have to accommodate benefit structure and supplemental insurance. The MedEncentive program promotes shared decision making by simultaneously incentivizing physicians and offering financial rewards (in the form of copay rebates ranging from \$10 to \$30) to patients who use web-based decision aids (Greene 2008). This incentive would need adjustment to account for the large percentage of Medicare beneficiaries who have supplemental coverage, but there is some evidence that it yields higher participation rates and cost savings (Greene 2009). Any incentive program would be an added cost but could decrease spending on net if patients opt for less-invasive and less-expensive treatment options.

Require providers to offer shared decision making for some services

Some analysts have suggested that shared decision making be a requirement rather than an option for some preference-sensitive decisions. They argue that patients should not receive preference-sensitive treatments unless they understand the potential risks and benefits the treatment entails. However, implementing payment or coverage restrictions might be difficult if physicians do not have the office infrastructure to facilitate shared decision making within FFS Medicare.

- The Commonwealth Fund (Schoen et al. 2007) proposes requiring FFS Medicare beneficiaries to use patient decision aids for certain high-cost, preference-sensitive conditions, including coronary revascularization for angina and lumbar spine surgery for low-back pain. Providers who perform

the procedure or are accountable for the patient's care would be held responsible for ensuring that the patient has complied. Providers who do not document that this process took place would be subject to a 10 percent reduction in Medicare payments for claims related to the procedure.

- Medicare could link coverage for some preference-sensitive conditions to use of shared decision making. Similar to coverage with evidence development, Medicare would cover specified procedures only with documentation that the patient has engaged in shared decision making with her physician.

As with performance incentives, CMS would have to define criteria to ensure that shared decision making met quality criteria. For example, it would need to verify that patient decision aids were objective, evidence based, and up to date. It would also need metrics to evaluate the effects of the strategy. It would need to account for cases in which beneficiaries are offered shared decision making but refuse to participate. One disadvantage is that this strategy would penalize physicians who do not have the office infrastructure to implement an efficient program of shared decision making. It could also penalize practices serving non-English-speaking populations. Currently, decision aids are not widely available in languages other than English. Finally, as noted earlier, if physicians are required to offer shared decision-making tools but do not support their use, the model is less likely to be effective.

Future work pertinent to shared decision making in Medicare

In future work, we plan to examine some of the challenges Medicare faces trying to communicate with beneficiaries about how their health care services are delivered and financed. In addition to decisions facing all consumers, Medicare beneficiaries must learn about the program and choose whether to obtain benefits from the traditional FFS program or enroll in a Medicare Advantage plan. They must decide whether to enroll in a separate drug plan. They also must determine whether they need supplemental coverage or whether they qualify for additional financial help from the government. They may find the amount of information they receive on all these issues abundant but difficult to synthesize.

Fraenkel and McGraw note that consumers tend to have a broader understanding of medical decision making than that encompassed by shared decision-making programs (Fraenkel and McGraw 2007). For example, they consider choice of provider a key decision they routinely make. In previous work, the Commission has documented the difficulties Medicare beneficiaries faced trying to choose a drug plan when Part D was implemented (Medicare Payment Advisory Commission 2007). An instrument like a decision aid, if recognized as objective and balanced, may help beneficiaries with this sort of choice. Consumers also consider whether to take a prescribed medication an aspect of personal choice. Thus, a broader definition of shared decision making may provide a useful perspective on issues like plan and provider choice and patient nonadherence to medication regimens. ■

Endnotes

- 1 This estimate of health literacy is based on a review of roughly 85 studies that measured health literacy using the Rapid Estimate of Adult Literacy in Medicine test or the Test of Functional Health Literacy in Adults.
- 2 To meet minimal inclusion criteria, the patient decision aid must:
 - Satisfy the Cochrane definition of a patient decision aid: Patient decision aids are interventions designed to help people make specific deliberative choices by providing information about options and outcomes that are relevant to a patient's health status and by clarifying personal values. They are intended to be adjuncts to counseling.
 - Have a development process that includes expert review.
 - Have an update policy.
 - Support statements with scientific evidence.
 - Disclose funding sources and conflicts of interest.
- 3 Conditions chosen include herniated disc, spinal stenosis, knee and hip osteoarthritis, prostate enlargement, prostate cancer, prostate-specific antigen (PSA) testing, uterine fibroids, abnormal uterine bleeding, chronic stable angina, early-stage breast cancer, and reconstructive surgery after a mastectomy. For more information, see http://www.hhnmag.com/hhnmag_app/jsp/articledisplay.jsp?dcrpath=HHNMAG/Article/data/02FEB2010/1002HHN_FEA_power&domain=HHNMAG.
- 4 The use of decision aids to help inform patients' decisions about PSA testing may be gaining traction. In February, the American Cancer Society issued revised guidelines for PSA testing that recommend that men use patient decision aids to help them make an informed choice about testing. The guidelines identify the type of information that should be included in these aids.

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