



# issue brief

## Choice in Medical Care: When Should the Consumer Decide?

In February 2007, AcademyHealth conducted a meeting on behalf of the Robert Wood Johnson Foundation to examine the role of consumer engagement in improving the quality of health care. In preparation for this meeting, five papers were commissioned on the following subjects: consumer activation, consumer choice of health plan and provider, consumer choice of treatment, patient navigation, and the appropriate role for consumers in the decision-making process. This issue brief is based on the paper exploring the appropriate role for consumers, which was authored by Floyd J. Fowler, Jr., Ph.D., and Diana L. Stilwell, M.P.H., of the Foundation for Informed Medical Decision Making.

### Current State of Medical Decision Making

Most people believe that patients should have the authority to make decisions regarding their primary care physicians, hospitals and health plans, yet there is little information available to help consumers make informed decisions. For example, consumers have limited access to relevant information about physicians' practice style and competency. They also lack adequate information about area hospitals, and most admit that they rarely refer to such information when choosing a hospital. Lack of information about health plans is also a concern. While efforts have been made to make information about health plans available to consumers,

much decision making is based on the information offered by employers.

While most agree that the patient should be the primary decision maker in their choice of doctor, hospital and health plan, there is not universal agreement on the appropriate role for the patient to play when it comes to choices about tests and treatments. Patients rarely have enough information to make informed decisions, and the current health care system does not usually support informed decision making.

In part, this reflects the traditional medical care model, wherein physicians diagnose diseases and prescribe treatments and patients comply with those recommendations. For a number of reasons, this model does not always serve the patient's interests. In fact, many medical decisions made today could be said to violate the basic ethical principle of patient autonomy, which refers to the right of patients to be given sufficient information about their medical conditions and treatment options to make autonomous decisions.

A more appropriate model is "shared decision making," which brings together the physician's clinical expertise and the patient's preferences for how to treat or manage a health problem. This model is preferable because it is more ethical and it results in decisions that better serve the patient's interests.



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While preferences for involvement in medical decision making vary, it is important that the patient's right to know be consistently respected. Of course, the context of the decision and the capabilities and preferences of the individuals involved will affect what the appropriate decision-support process will look like. However, for all decisions, whether being made by a physician or a patient, the information relevant to understanding and considering the treatment options and potential effects of those treatments should be provided to the patient. Moreover, arming patients with appropriate information is one important step in getting them more involved in decisions about their health care.

Medical decisions can be sorted into three categories: choices about treatment, choices about screening and choices about chronic disease care. While the issues facing patients may be different, the importance of getting them informed and involved remains consistent.

### Treatment Choices

The appropriate role for patients partly depends on the problem to be addressed: Is it a condition that primarily affects quality of life or is it life threatening? The patient's role also depends on how the effects of the various interventions compare with each other: Do several options offer similar benefits and possible side effects or is one option both more effective and more risky compared with the others?

In all cases, the physician's role is to diagnose the problem, define a set of appropriate treatment options and support the patient in choosing an approach. Virtually all significant medical interventions have plausible alternatives. The options usually have different pros and cons and different quality-of-life implications for the patient. The patient is in the best position to weigh those alternatives. The patient's role should be to consider how each of the options and their possible outcomes will affect them and share that information with the provider. In nearly all cases, the primary decision maker about which treatment to choose should be the patient, even in cases where the patient's preference differs from that of the provider or the expert groups that issue treatment guidelines. Working together, the patient and provider can

select the option that will most likely provide the outcome desired by the patient.

### Screening

Screening tests offer an opportunity to detect and treat disease in apparently healthy people. In some cases, early detection via screening can lead to improved outcomes, but screening can also cause harm. In addition, screening for some conditions offers sizeable benefits at the population level, but these benefits might be judged to be relatively small at the individual level. To make an informed choice about screening, patients and providers need to consider the individual's chance of disease and death without screening, how screening would change that outcome, and the possible risks involved.

Depending on the possible benefits of early detection compared with the possible harms of screening, different patients might choose different approaches to screening. While some patients may simply do what the experts or their own physicians recommend, all patients should be informed of their options and determine the degree to which they want to be involved in these choices.

### Chronic Disease Care

For the majority of chronic diseases, patients themselves provide most of the day-to-day care. Physicians know the recommended evidence-based treatments but often have little understanding of how these interventions affect individual patients. For example, physicians spend about two hours per year with their diabetic patients, but these patients spend about 8,758 hours managing their own health without the guidance and support of a provider.

Guidelines and pay-for-performance initiatives tend to assume that all patients in a population place the same value on avoiding adverse outcomes, which tend to occur in the future, and are similarly willing to accept the costs of avoiding them, which are usually experienced in the short run. These guidelines offer little advice for how to provide patients with a range of options that can achieve similar outcomes and can be tailored to patients' individual situation and preferences. Clinical outcomes chosen as measures of quality are often arbitrary

points along a continuum rather than clear-cut points between good and bad care.

In making choices about how to manage chronic diseases, patients and providers need to collaborate. They need to share information about medical risks and what is important to patients to help make informed choices that maximize both short-term and long-term goals. And they need to develop individualized guidelines for "rational noncompliance" that are acceptable to both parties. ,

### Concerns About Involving Patients

There are many concerns about increasing the involvement of patients in the medical decision-making process. The three most common arguments against increased patient involvement are that: 1) patients will not make the right choices, 2) patients will increase medical costs if they have more control, and 3) it is too difficult and expensive to inform and involve patients in their decisions.

### Making the Right Choices

Encouraging patients to take a larger role in medical decision making could increase choices that cause harm to the patient. For example, the right to choose quality of life over length of life is a fundamental patient right. Giving patients a larger role in medical decisions brings with it an ethical responsibility to minimize avoidable ignorance about the options and their consequences and not offer options for which there is no evidence of benefit in either length or quality of life.

Another important concern is that patients may place a higher value on avoiding harm and a smaller value on the possible benefit of a proposed treatment. This is not a bad choice if it is informed and reflects their values.

### Financial Implications of Informed Patients

Some argue that increasing the role of patients in medical decision making will increase health care costs. The evidence on this topic to date is not definitive. However, there is reason to hypothesize that giving patients more say in their care is likely to decrease costs. The current physician reimbursement system provides

incentives for physicians to perform more services, not fewer. Therefore, the current approach would not seem to encourage cost savings. Moreover, numerous trials using decision aids have found that patients consistently choose fewer tests and surgical interventions when they are informed than when they receive “usual care.”

### Logistics of Informing Patients

The most compelling argument against increasing patient involvement is its logistical difficulties. Informing and supporting patients faced with complex decisions requires significant time and resources, which are rarely reimbursed under current systems. Five key elements have been identified as necessary to involve and inform patients:

1. Patients need to know a decision is being made in which they could take part. In many cases, neither patients nor physicians are fully aware of the points at which decisions could or should be made. Few record-based methods exist for physicians to track screenings of patients, and those that do exist are focused on chronic care. Additionally, when a physician prescribes a screening or treatment, patients may not understand that other options may exist.
2. Patients need to understand the decision. One of the best demonstrated methods of informing patients of their health care options is the use of decision aids. In their many forms, decision aids present the positive and negative attributes of each option; provide accurate information on the probabilities of various outcomes; and elicit discussion between the patient, their family and their provider regarding how their values and personal characteristics may affect their choice.
3. Patients need to understand their interests in the decision. Many patients do not have a complete understanding of what their health care options mean to them because they have not evaluated potential outcomes based on their personal priorities. They do not know that their preferences matter and they need time to integrate the things they care about into the decision-making process.
4. Patients may need someone to help answer their questions. Even when high-quality information is presented to patients, they may still need to talk with someone about how that information applies to their specific clinical situation. Whether it is a physician, a nurse, or a trained coach or counselor, access to an informed person to talk through the decision with is quite important.
5. Patients need to work with providers who respect their right to be responsible for their own care.

Multiple barriers must be overcome in the current system and in systematic reform efforts before patients can be fully involved in the medical decision-making process. A number of promising programmatic initiatives are underway throughout the country that could serve as best practice models for additional initiatives.

### Conclusion

Arming patients with the knowledge and support to make informed choices in their health care is the right way to make decisions and will result in decisions that better serve patients. There are models that demonstrate how decisions can be routinely supported in both primary care and specialty practices. There is also reason to believe that the cost of treatment will be lower when patients take a more active role in the decision-making process. However, providing widespread decision support to patients will be a challenge unless there is a broader consensus on the importance of informed and involved patients and until decision support services are routinely supported by insurance.

### About the author

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