

By Floyd J. Fowler Jr., Carrie A. Levin, and Karen R. Sepucha

Informing And Involving Patients To Improve The Quality Of Medical Decisions

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ABSTRACT Good-quality care requires that procedures, treatments, and tests be not only medically appropriate, but also desired by informed patients. Current evidence shows that most medical decisions are made by physicians with little input from patients. This article describes issues surrounding informed patient decision making and the steps necessary to improve the way decisions are made. Creating incentives for providers and health care organizations to inform patients and incorporate patients' goals into decisions is critical. Patient surveys are needed to monitor the quality of decision making. Health information technology can help by collecting information from patients about their symptoms, how well they understand their options, and what is important to them, and sharing that information with providers. We review public and private developments that could facilitate the development of tools and methods to improve patient-centered care.

Floyd J. Fowler Jr. (fjfwol@fimd.org) is a senior scientific adviser to the Foundation for Informed Medical Decision Making, in Boston, Massachusetts.

Carrie A. Levin is director of research at the Foundation for Informed Medical Decision Making.

Karen R. Sepucha is director of the Health Decision Sciences Center, Massachusetts General Hospital, and an assistant professor of medicine at Harvard Medical School, in Boston.

Good-quality care requires that procedures and tests be medically appropriate and executed safely—two criteria that have often been the primary focus of quality improvement efforts. However, appropriateness alone does not mean that the care is necessary or desired by the patient. High-quality medical care must go further and ensure that every procedure, treatment, and test ordered also meets patients' goals for care. High-quality medical decisions require that patients be fully informed and involved in the decision-making process.

The importance of involving patients in decision making was underscored as early as 1982 by the President's Commission for the Study of Ethical Problems in Medicine.¹ The proposition has since been reaffirmed and deepened, with subsequent publications and the support of organizations such as the Institute of Medicine,^{2,3} the National Quality Forum, and the American Medical Association.⁴

We address the questions of why shared decision making is so important to the quality of

health care and what steps need to be taken to ensure that patients routinely have a voice in the decisions about their care.

Shared Decision Making

Shared decision making recognizes that medical decisions require interaction between patients and their doctors; that decisions be informed by the best available clinical evidence; and that decisions reflect the individual patient's well-considered goals and concerns.^{5,6} Identifying the medical problem and laying out the reasonable options are primarily the responsibility of the physician. Patients have the primary responsibility for identifying and conveying their goals and concerns relevant to the decision they are facing. Patients and physicians each have important roles to play in the process and must be receptive to each other's input.

To help illustrate the issues and trade-offs that doctors and patients must consider in shared decision making, we use the example of taking a statin to reduce elevated low-density lipo-

protein (“bad”) cholesterol. There have been numerous clinical trials designed to assess the effects of taking statins to reduce the rate of heart attacks and deaths from heart disease. The results vary depending on the mix of patients studied and which drug is being tested. However, all studies agree that people who have not had a heart attack or have no notable heart risk factors other than elevated cholesterol benefit much less from taking statins than those who have heart disease.

For example, if 200 people with elevated cholesterol levels, but no other indications of heart disease, took a statin every day for five years, one of them would avoid a heart attack or death (199 would be unaffected). In contrast, if 200 people with a history of heart disease or heart attack took a statin for five years, between two and ten would avoid a heart attack or death, depending on their clinical profiles.^{7,8}

With or without heart disease, there is a decision to be made about whether or not to take a statin to lower cholesterol. The best option cannot be determined without the patient’s input to determine how much weight to assign to each component—benefits, risks, and financial costs of taking statins or incurring other health-related costs.

This example is typical of the kinds of trade-offs that arise in the case where medication is a treatment option. But there are trade-offs for almost all medical decisions, including surgery and cancer screening. For example, patients with a herniated disk that causes back and leg pain have to weigh the quicker fix that surgery may bring against the risks of surgery and the likelihood that the back will heal itself in time without surgery. Additional considerations include the cost of the surgery, the time away from work or other activities, and limitations on activities under either option.⁹

Patients differ from one another, and often from their physicians, in the weights they assign to factors that bear on a decision. To get the decision that best serves the patient, it is necessary to have the patient informed and involved in the decision-making process.

Of course, a consequence of giving patients an informed voice is that they might not always choose the safest, most effective, or most cost-effective options. Thus, there are implications for both physicians and health plans when patients are more actively involved in medical decision making.

For example, it may be frustrating to physicians when recommendations that they believe in, or that are supported by the evidence, are not chosen by the patient. (Of course, patients do not always follow physicians’ recommendations any-

way.) Guidelines for care, therefore, need to be adjusted to allow for patients’ preferences so that physicians are not penalized when patients choose care options that are not favored by the evidence.

Similarly, health plans may want to limit coverage of some treatments that patients want if the evidence does not support the treatments. It’s worth noting, however, that experiments with informing patients facing surgical decisions find that, on average, informed patients tend to opt for less surgery than patients in “usual care.”¹⁰ This means that at least in the case of surgery, more-informed patients may lean toward more “conservative” treatment options that cost less. Whatever choices patients make, a core principle of shared decision making is that the value of benefits and risks should be determined by those who have to live with them.

The remainder of this article explores the steps needed to ensure that patients are routinely informed and involved in decisions about their medical care, so that high-quality medical decisions result.

The Problem

For patients to have a meaningful say in their medical decisions, three essential conditions must be met. First, they have to be informed. Specifically, they have to be given an objective, unbiased presentation of reasonable options to consider and the pros and cons of those options. Second, once informed, patients have to spend some time to consider their goals and concerns and how each option is likely to play out with respect to those goals and concerns. Third, they have to have an interaction with their providers in which their goals and concerns are shared and incorporated into the decision-making process.¹¹

Unfortunately, the information we have about the way medical decisions are made in the United States makes it clear that those steps do not happen very often. The 2007 DECISIONS survey carried out by the University of Michigan provides relevant evidence about the quality of common decisions involving medical care.¹¹

A national sample of 3,010 adults older than age forty were asked whether they had talked with a doctor in the preceding two years about any of nine decisions: three cancer screening decisions (for breast, colon, or prostate cancer); three long-term medications (for depression, high blood pressure, or elevated cholesterol); and three surgical procedures (for back pain, cataracts, or hip/knee replacement). For up to two such decisions they had confronted, respondents were asked a series of questions about what they knew, their goals, and their interac-

tions with providers.¹¹

With respect to the first essential step, being informed, respondents were asked four or five questions, depending on the decision, about things that clinical experts thought patients should know before making an informed decision. For example, in the case of medication for elevated cholesterol, patients making a decision should know the common side effects of the drug and how much their cholesterol readings differ from “normal.” The median number of correct answers was one for eight of the nine decisions. To provide a sense of the problem, of those who had made a decision about taking statins for high cholesterol, only 57 percent knew what a normal cholesterol level was, and only 17 percent could name the most common side effect of statins.¹²

Patients’ reports in the survey about their interactions with health care providers did not suggest a cooperative or shared decision-making process. For the most part, patients reported that their physicians framed the decision in favor of the intervention being discussed, instead of presenting it as just one option among several, including no treatment.

Across all nine decisions, 78–85 percent of respondents reported that physicians made a recommendation. Moreover, when a recommendation was made, it generally was reported as having been in favor of having surgery (recommended about 65 percent of the time for all three types of operations), taking medication (recommended 86–93 percent of the time), or having screening (recommended 94–99 percent).¹³

Consistently, respondents reported that physicians tended to discuss the reasons to have the intervention or test much more than they discussed reasons why patients might not want to. Discussions of why patients might not want to have a cancer screening test were particularly rare; only 20–32 percent reported such discussions. Perhaps most important, for five of the six nonsurgical decisions, a majority of respondents did not think they had been asked to express an opinion about what they wanted to do (the lone exception was for decisions involving medication for depression).¹³

There are some limitations to the DECISIONS study. The major one is that it depends on patients’ recall, and their reports can be in error. However, Clarence Braddock and colleagues examined recorded interactions between patients and their doctors, and they reported on the extent to which patients and providers engaged in shared decision making. Their results look very similar to the picture painted by the DECISIONS survey, suggesting large gaps in the quality of decision making.¹⁴

Using Decision Aids

Physicians typically do not have time and often lack the skills to present a complete, balanced presentation of the pros and cons of reasonable medical options. To address the problem of patients’ not being given complete, objective information, one obvious step is for providers to give their patients so-called patient decision aids: high-quality decision-support material to supplement the office visit. The information can be in audiovisual form or on paper; it can be delivered as a hard copy or made available on the Internet. It is important that the information be unbiased, complete, and presented in a form readily understandable by a wide range of people. In fact, there is now considerable evidence, based on more than fifty-five randomized clinical trials, that when patients are given good-quality decision aids, they are more informed and participate more in decision making than do patients in usual care.¹⁰

Exposing patients to good information, although highly valuable, is not enough. Once patients have had an opportunity to learn about their options, it is also necessary to have an interaction between providers and patients that incorporates patients’ goals and concerns into the decisions that are made.

Using Health Information Technology

Initiatives to identify meaningful uses for health information technology may offer one important tool for facilitating high-quality decision-making processes. To date, most of the initiatives with information technology have focused on making the information currently stored in medical records available electronically. Patients’ medical records are mainly a repository for providers’ notes, tests, treatments ordered and completed, and the results. In addition, some electronic records aim to improve clinical decisions by embedding into the system clinical guidelines and programming reminders for physicians to implement effective care.

TRIGGER DELIVERY OF INFORMATION A way in which health information technology can improve decision making is to “trigger” the delivery of relevant health information directly to patients at the point when they need to think about making a medical decision. In the primary care division at Massachusetts General Hospital, when providers enter a new problem from a list of problem conditions and symptoms into a patient’s electronic health record, a reminder icon appears next to the problem to indicate the availability of a relevant decision aid. With one click of the mouse, a decision aid can be prescribed and

is mailed directly to the patient. A note is automatically generated for the health record indicating the delivery of the aid.¹⁵

COLLECT AND STORE INFORMATION Health information technology can also be used to collect and store information provided by patients. Three specific kinds of information in this context could improve the quality of decision making and should be considered in the design of electronic health record systems to augment current uses.

► **DECISION WINDOWS:** First, information is needed that documents symptom severity and identifies potential “decision windows.” One of the challenges to providing good decision support is that it is difficult to predict or know when a patient has a decision to make. Such “decision windows” are triggered when certain symptom thresholds are reached. One excellent use of electronic record systems would therefore be to collect and track self-reported symptom severity for patients who have symptom-driven conditions such as arthritis, back pain, benign enlarged prostates, knee pain, or benign uterine conditions. For example, patients at the Spine Center at Dartmouth-Hitchcock Medical Center fill out a standard questionnaire about their symptoms each time they visit the clinic. The results are tracked, enabling patients and doctors to see how symptoms such as pain and functional limitations are changing over time. This type of systematic documentation enables targeted decision support at appropriate times.

► **WHAT PATIENTS KNOW:** Another valuable use of technology is to collect information about what patients know and do not know about their medical conditions and treatment options. When patients face a decision, they can be asked a short set of questions to assess whether they understand the key issues related to the decision. If collected during the decision-making process, this information could enable providers to identify critical gaps in patients’ knowledge that they can correct or fill before a decision is made. If collected after the decision-making process (for example, at the time of or shortly after surgery), this information could be used to measure how well providers were informing their patients and provide a basis for quality improvement efforts.

► **WHAT PATIENTS WANT:** There is a similar need to systematically collect and record patients’ priorities relevant to the decision they are facing. For decisions with two or more options, there are usually a relatively small number of goals and concerns that are likely to be most relevant to the choice. If this is done during the decision-making process, asking patients about their goals and concerns helps them think these matters through. Sharing their goals and con-

cerns with providers helps to ensure that physicians know patients’ preferences before a decision is made. If patients are asked again about their goals and concerns after the decision-making process—for example, shortly after surgery or some other kind of intervention—the information can be used to assess how well the treatment decisions reflected the priorities of the patients and, like measures of knowledge, form the basis for quality improvement efforts.

Surveys To Assess Patients’ Knowledge And Goals

It is possible to develop short survey instruments to assess patients’ knowledge and goals. Decision-quality survey instruments have been developed and evaluated for a dozen common medical conditions, including treatment of osteoarthritis and breast cancer.^{16,17} For example, before a physician works with a patient who has a herniated disk to make a treatment decision, a survey could be used to determine whether the patient knows the following: (1) surgery and conservative management are both reasonable options; (2) for most people, surgery will relieve pain faster than nonsurgical approaches; (3) the back will probably heal itself over time, and the pain will be relieved even without surgery; (4) surgery relieves pain about 80 percent of the time; and (5) for most people, doing normal activities will not make the herniated disk worse.

A guide to patients’ goals and concerns could include responses to the following: (1) How much does back and leg pain interfere with doing things that are important to the patient? (2) How important is it for the patient to have quick pain relief? (3) How does the patient feel about having surgery, including the risks of complications and dealing with recuperation? (4) How would the patient feel about living with pain for an extended period while the back heals on its own?

These applications are not hypothetical or unrealistic. For the past five years, breast cancer patients at the Dartmouth-Hitchcock Medical Center have completed decision-quality instruments that assessed their knowledge and goals after viewing a decision aid and before they met with a surgeon to discuss treatment. Their answers are available to the surgeon so that the surgeon can correct misinformation and make sure that the discussion of treatment options takes into account what is most important to the patient.¹⁸

Accountability And Quality

Having good-quality decision aids available is valuable. Having good technological support

for collecting and sharing information between physicians and patients can also be an important aid to progress. However, sharing decisions will also represent a real culture change for most physicians and patients. There are many competing demands on providers' time, and their resulting need to prioritize often means that some activities do not get their full attention.

Having providers check off boxes indicating that patients have been informed and involved will not necessarily constitute credible evidence that patients have really been informed and involved in decisions. Even with good intentions and supportive resources, it will be easy for many important decisions to be made in the old-fashioned way: Patients will not be informed, and there will be little patient-centered discussion of what to do; physicians will tell patients what they think they should do, and patients will do it.

For these reasons, in order to improve decision making, it is also essential to have a feedback mechanism that provides reports on the quality of the decision-making process.

There are four key elements needed to measure the quality of the process of decision making: the extent to which all the reasonable alternatives were presented for consideration; the extent of discussion of the reasons one might want an intervention; the extent of discussion of the reasons one might not want an intervention; and the extent to which the patient's views and preferences were included in making the decision.

The most promising mechanisms for measuring the quality of the decision-making process are the surveys conducted as part of the Consumer Assessment of Healthcare Providers and Systems (CAHPS). These are standardized surveys of patients' experiences with ambulatory and facility-level care developed by the Agency for Healthcare Research and Quality and carried out annually by most health plans. The plans then submit the results to the National Committee for Quality Assurance as part of the process for getting a quality assurance rating.¹⁹ The health plan survey does not currently include questions about shared decision making; nor does it provide data about individual providers or provider groups. However, two other surveys under the CAHPS umbrella have the potential to provide the information that is needed.

The National Committee for Quality Assurance and CAHPS collaborators are testing a new instrument designed to evaluate how well primary care providers meet the standards for a patient-centered medical home.¹⁹ This instrument includes a series of questions that specifically address how decisions are made and that were adapted from the questions used in the

DECISIONS survey mentioned earlier.¹¹ It remains to be seen how and how widely this survey will be used. However, the potential exists for the survey to provide solid information about the extent to which shared decision making is happening in primary care practices. The efforts may lead to incentives to fund such surveys to qualify for certification as a medical home.

Another option to provide feedback on the quality of surgical decision making is the Hospital CAHPS, or HCAHPS, surveys.¹⁹ The basic HCAHPS survey instrument covers many aspects of the inpatient experience. A survey specifically for surgical patients has been vetted through the CAHPS approval process. The surgical survey probes how decisions are made. Including that same series of questions in the HCAHPS surveys would provide feedback on the quality of surgical decisions at the hospital level.

A downside of the current HCAHPS survey design is that it does not include day surgery patients, who constitute an important part of the surgical population. Adding samples of those patients to the HCAHPS design would strengthen the potential of the surveys to assess how well the decision-making process is carried out.

How Can We Make Change Happen?

Although altering the way decisions are made would constitute a profound change in the practice of medicine, many elements already in place could help make the transformation happen. Some of these, such as expanding the role of health information technology, were discussed above. Below we discuss several more public and private developments that could contribute to efforts to improve medical decision making through greater patient involvement.

AFFORDABLE CARE ACT Shared decision making is among the delivery system reforms included within the new Center for Medicare and Medicaid Innovation, which was authorized under section 3021 of the Affordable Care Act of 2010 and further amended under section 10306 of the Health Care and Education Reconciliation Act of 2010. The purpose of the center is to evaluate payment and service delivery innovations aimed at reducing costs while maintaining or improving quality.

A variety of health care delivery models will be piloted under the new center's initiatives. One of the models to be tested includes helping patients make informed decisions by paying providers for using decision aids. The innovation center has \$10 billion appropriated over the next decade to test and implement new models such as this one. We are hopeful that at least some of the pilots will

feature the routine use of decision aids and decision support from providers.

A shared decision-making program was authorized, but not appropriated, under section 3506 of the Affordable Care Act. Specifically, the legislation establishes a program at the Department of Health and Human Services for the development, testing, certification, and promotion of patient decision aids to help patients, caregivers, and physicians incorporate patients' preferences and values into medical care plans. Working to ensure that funding is appropriated for this program would greatly advance the quality of decisions.

Another unfunded component of the Affordable Care Act is its quality provisions (section 3013), which authorize the secretary of health and human services to award grants and contracts for purposes of developing, improving, updating, or expanding quality measures, with priority on quality measures that assess the use of information in shared decision making and the patient-centeredness of care, among other things. Funding these provisions would help spur the development and acceptance of patient involvement as an integral part of the quality of medical care.

COMPARATIVE EFFECTIVENESS RESEARCH The Patient-Centered Outcomes Research Institute is funded under section 3590 of the Affordable Care Act to conduct research on the comparative effectiveness of various medical interventions. Such information provides the foundation of shared decision making by developing the evidence-based information that patients and providers need to make the best decisions.

In addition to supporting the goal of developing a sound evidence base for decision making, the institute could further help the cause of patient-centered decision making by supporting research in several areas, including improving patient decision aids and advancing our understanding of how best to translate medical evidence for patients and physicians.

DELIVERY SYSTEMS The patient-centered medical home has emerged as potentially a new standard for primary care, and shared decision making is a key element. Payers should be encouraged to create incentives for primary care providers to deliver care that meets the patient-centered medical home standards and supports shared decision making.

Accountable care organizations are also emerging as a part of the future of health care. They create the opportunity to expand shared decision making beyond primary care into specialty care and hospital systems. They have yet to be fully defined. One important step would be to incorporate the standards for shared decision

making into the definition of an accountable care organization.

STATE ROLE As noted above, under the Affordable Care Act, the federal government will have opportunities to play a leadership role in developing innovations that promote patient involvement in medical decision making. States can also provide leadership in this area and have already begun to do so.

Lawmakers in Washington State, for example, recognized that traditional approaches to informed patient consent were not adequate in terms of incorporating patients' feedback into medical decisions. This recognition was the impetus for a 2007 law that promotes the use of shared decision making with approved decision aids as a way to better inform patients and engage them in health care decisions.²⁰ A demonstration involving several health plans and health providers is now under way in the state to help assess how shared decision making affects patient choices.

Other states are considering legislation in this area as well.²⁰ This is a positive sign, and further state experimentation should be encouraged, especially during the formative stages of this movement. The federal government should take note of these efforts as the science matures to ensure that knowledge gained from them is incorporated into federal policies and that best practices are applied consistently, rather than heterogeneously across states.

SURGERY AND HOSPITAL CARE Although many more decisions are made in primary care than in specialty care, the impact of surgical decisions on patients and medical expenditures is significant. The Centers for Medicare and Medicaid Services has already established a routine survey of discharged patients as a way of adding patient experience to the criteria by which hospitals are evaluated (Hospital CAHPS).¹⁹ The addition of a brief survey module about the decision-making process for patients who had surgery might be one of the best and easiest ways to increase the extent to which patients are informed and involved in decisions about their medical care.

Conclusion

The starkest example of a medical error is to operate on the wrong patient—for example, when a surgeon performs back surgery on the patient in bed A when it is the patient in bed B in need of the procedure for a herniated disc. We would argue that it is equally bad to perform any operation on a patient who, had he or she been informed and given a voice in the decision, would not have chosen to have the operation, even if it were a medically appropriate choice.

That, in our view, also is essentially operating on the wrong patient. The “right” patients for surgery are the ones who are clinically appropriate and who made an informed choice that surgery is the best way to treat their condition. The way to avoid such medical errors is to make sure that every patient is fully informed and involved in making the important decisions about his or her medical care.

We argue that among the most important reforms needed to improve medical care are those that would inform and amplify the voice of the patient when medical decisions are made. To make that happen, patients facing decisions should routinely be given decision-support materials that objectively lay out the options in clear, accessible terms. Reimbursement by pub-

lic and private payers needs to cover the cost of providing decision-support materials and the cost of physicians’ meeting with patients to decide what decision will best serve patients’ interests. In addition, the technology systems in medical settings should be designed to collect information from patients about the decisions they are facing, their health status, what they know, and what they care about.

Finally, we need to collect systematic data from patients about decision quality and the process of decision making to which they are exposed. All of these elements—the tools and surveys—are currently in routine use in select organizations. Now, we need a commitment to putting these elements in place on a widespread basis. ■

Floyd Fowler and Carrie Levin are employed by the not-for-profit Foundation for Informed Medical Decision Making. Karen Sepucha has

research grants from the foundation. Through a commercial agreement with Health Dialog, a for-profit company, decision aids created jointly by Health

Dialog and the foundation are distributed as part of services provided through health plans and employers to patients facing medical decisions.

NOTES

- 1 President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Making health care: the ethical and legal implications of informed consent in the patient-practitioner relationship. Washington (DC): Government Printing Office; 1982.
- 2 Hurtado MP, Swift EK, Corrigan JM, editors. Envisioning the national health care quality report. Washington (DC): National Academies Press; 2001.
- 3 Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington (DC): National Academies Press; 2001.
- 4 American Medical Association. 2010 strategic issues: getting the most for our health care dollars [Internet]. Chicago (IL): AMA; 2010 [cited 2011 Mar 14]. Available from: <http://www.ama-assn.org/ama/pub/about-ama/2010-strategic-issues/health-care-costs.shtml>
- 5 Mulley AJ. Assessing patients’ utilities: can the ends justify the means? *Med Care*. 1989;27(Suppl 3):S269–81.
- 6 Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med*. 1997;44(5):681–92.
- 7 Hadler NM. Worried sick: a prescription for health in an overtreated America. Chapel Hill (NC): University of North Carolina Press; 2008.
- 8 Rifkin E, Bouwer E. The illusion of certainty: health benefits and risks. New York (NY): Springer Press; 2007.
- 9 Weinstein JN, Lurie JD, Tosteson TD, Tosteson AN, Blood EA, Abdu WA, et al. Surgical versus nonoperative treatment for lumbar disc herniation: four-year results for the Spine Patient Outcomes Research Trial (SPORT). *Spine*. 2008;33(25):2789–800.
- 10 O’Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2009;3:CD001431.
- 11 Zikmund-Fisher BJ, Couper MP, Singer E, Levin CA, Fowler FJ, Ziniel S, et al. The DECISIONS study: a nationwide survey of US adults regarding nine common medical decisions. *Med Decis Making*. 2010;30(5 Suppl):S20–34.
- 12 Fagerlin A, Sepucha KR, Couper MP, Levin CA, Singer E, Zikmund-Fisher BJ. Patients’ knowledge about 9 common health conditions: the DECISIONS survey. *Med Decis Making*. 2010;30(5 Suppl):S35–52.
- 13 Zikmund-Fisher BJ, Couper MP, Singer E, Ubel PA, Fowler FJ, Levin CA, et al. Deficits and variations in patients’ experience with making 9 common medical decisions: the DECISIONS survey. *Med Decis Making*. 2010;30(5 Suppl):S85–95.
- 14 Braddock CH 3rd, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: time to get back to basics. *JAMA*. 1999;282(24):2313–20.
- 15 Barry M. Implementation of shared decision-making in primary care at MGH: prescribing activity and preliminary patients survey results. Paper presented at: 4th International Shared Decision Making Conference; 2007 May 30–June 1; Freiburg, Germany.
- 16 Sepucha KR, Levin CA, Uzogara EE, Barry MJ, O’Connor AM, Mulley AG. Developing instruments to measure the quality of decisions: early results for a set of symptom-driven decisions. *Patient Educ Couns*. 2008;73(3):504–10.
- 17 Lee C, Barry M, Cosenza C, Dominik R, Levin C, Mulley A, et al. Development of instruments to measure the quality of breast cancer treatment decisions. *Health Expect*. 2010;13(3):258–72.
- 18 Collins ED, Moore CP, Clay KF, Kearing SA, O’Connor AM, Llewellyn-Thomas HA, et al. Can women make an informed decision for mastectomy? *J Clin Oncol*. 2009;27(4):519–25.
- 19 Agency for Healthcare Research and Quality. CAHPS survey products: CAHPS survey instruments [Internet]. Rockville (MD): AHRQ; 2010 [cited 2011 Mar 15]. Available from: https://www.cahps.ahrq.gov/content/products/Prod_Intro.asp?p=102&s=2
- 20 Kuehn BM. States explore shared decision making. *JAMA*. 2009;301(24):2539–41.

ABOUT THE AUTHORS: FLOYD J. FOWLER JR., CARRIE A. LEVIN & KAREN R. SEPUCHA



Floyd J. Fowler Jr. is a senior scientific adviser to the Foundation for Informed Medical Decision Making.

Floyd Fowler and his coauthors propose steps to eliminate one barrier to quality health care: namely, the failure to educate patients fully about their options when they face decisions about procedures, treatments, and tests. By default, the authors say, that deficiency leaves doctors as primary decision makers, with little input from patients—even though it is patients who must live with the consequences of those choices.

Fowler says that in twenty-five years of conducting interviews with patients, he has learned that when they are fully informed, “they often would make different decisions than when they are not informed or when they delegate the decision to doctors. There is no way doctors can know what patients’ values are, or what their priorities are, without talking to them,” he adds.

Fowler is a senior scientific adviser to the Foundation for Informed Medical Decision Making, a Boston-based nonprofit whose mission is to amplify the patient’s voice in health care

decisions. He was president of the foundation during 2002–09. Since 1971 he has also been a senior research fellow at the Center for Survey Research at the University of Massachusetts in Boston, and he was the center’s director for fourteen years.

Fowler is the author or coauthor of four widely used books on survey research methods. He also has been a major contributor to research on patient outcomes and how patients are affected by the treatments they receive. He has a doctorate in social psychology from the University of Michigan.



Carrie A. Levin is director of research at the Foundation for Informed Medical Decision Making.

Carrie Levin is director of research at the Foundation for Informed Medical Decision Making, overseeing the design, collection, analysis, and dissemination of research. Her current research interests include determining how medical decisions are made, measuring decision quality, and integrating the use of decision aids into routine clinical care. She received a doctorate in

health services research, policy, and administration with emphasis on long-term care and health economics from the University of Minnesota.



Karen R. Sepucha is director of the Health Decision Sciences Center, Massachusetts General Hospital.

Karen Sepucha is director of the Health Decision Sciences Center in the General Medicine Division at Massachusetts General Hospital and an assistant professor of medicine at Harvard Medical School. Her research and clinical interests involve developing and implementing tools and methods to improve the quality of important medical decisions made by patients and clinicians.

Sepucha was the medical editor for an award-winning series of five breast cancer patient decision aids developed by the Foundation for Informed Medical Decision Making. She has a doctorate in engineering–economic systems and operations research at Stanford University, with a focus on decision sciences.