



# issue brief

## Navigating Health Care: Why It's So Hard and What Can Be Done to Make It Easier for the Average Consumer

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. This issue brief is based on the paper exploring the challenges faced by consumers as they attempt to navigate the health care system, which was authored by Shoshanna Sofaer, Dr.P.H.

### Carving Out a Role for the Health Care Consumer

In the last several decades, efforts have been made to reduce rapidly escalating health care costs by applying pressure to various players in the sector. These efforts have been largely inadequate. In 2005, total national health expenditures rose 6.9 percent—two times the rate of inflation—and represented 16 percent of the gross domestic product. Furthermore, the overall financing and affordability picture for health care in the United States looks bleak.

More recently, policy-makers and researchers have begun to examine the relationship between health care cost and the quality of care received. In the discussion of pos-

sible approaches to reducing the former while improving the latter, the direct role of health care consumers has assumed a more prominent place. Previously, the patient—the central player in the health care space—was not seen as part of the solution. Now certain health care stakeholders have come to believe that patients need to take a more active role in all parts of their care. Some efforts in this area are intended to make consumers more aware of the costs associated with their use of health care services and selection of providers (e.g., “consumer-directed” health plans), while others focus on improving patient experiences and clinical outcomes (e.g., patient self management, shared decision making between patients and providers and greater patient “activation”).

Taken together these efforts may foster some improvements, but none constitute a big-picture “fix” for the cost/quality problems that currently exist, nor do they introduce the elements of ease and continuity that are so lacking for consumers trying to get care in today’s highly fractured health care sector. Perhaps this challenge—as seen from the health care consumer’s perspective—is best expressed by Jessie Gruman, Ph.D., who laments that “being a patient in the United States is like being drop-kicked into a foreign country. You don’t know the language, you don’t have a map, you can’t tell who’s in charge, and all you want to do



Robert Wood Johnson Foundation



AcademyHealth

is go home.” Fixing discrete segments of the sector may do little to improve this experience, but there is hope that a broader understanding of patients’ experiences, as they move through entire episodes of care and beyond, will help inform potential policy solutions.

### **Patient Navigation: What Is It and Why Is It Important?**

The concept of patient navigation has emerged as a way of characterizing the experiences of consumers in health care. For the purposes of this issue brief and the paper on which it is based, patient navigation is defined as “the process(es) by which patients and/or their health caregivers move into and through the multiple parts of the health care enterprise in order to gain access to and use its services in a manner that maximizes the likelihood of gaining the positive health outcomes available through those services.” Given the highly fractured and—to many—inscrutable nature of the U.S. health care sector, this process is fraught with challenges for most consumers, especially those who are sick, stressed, busy with their everyday lives or otherwise disadvantaged in taking on the tasks involved.

For patients to get timely, appropriate, affordable and quality care, they must be able to navigate the health care system. When it is too burdensome, patients and their caregivers respond by delaying or failing to get needed care or by seeking care in inappropriate but more easily accessible settings, such as emergency departments. Navigation challenges may also inhibit the capacity of certain individuals more than others, which can exacerbate health disparities. This leaves many vulnerable to the clinical consequences of poorly navigated health care. For example, those with limited English proficiency face the additional challenge of literally understanding what they need to do to gain access to appropriate care. It is no wonder that, on average, Americans receive appropriate health care only about half the time.

In addition to poor clinical consequences, health care efficiency is also seriously compromised by poor navigation. An enormous amount of time and energy is expended in trying to explain the workings of the health care system to patients and their caregivers. Just think of all the forms that people need

to read, understand and sign. They often end up signing whether they understand a form or not. Despite the system’s effort to make things clear up front, the complexity of most situations leads to problems or miscommunications that need to be untangled later. These problems often result in overuse, underuse or inappropriate use of services (e.g., duplication of diagnostic tests, missed physician visits and visits that are useless because necessary information has not arrived on time). All this, in turn, undermines the goal of getting value out of every health care dollar.

### **Why Is Navigation of Health Care So Hard?**

To understand why navigating health care is so hard, it is instructive to think about providers—both individuals and organizations—in the context of organizational theory. We know that all organizations need to both specialize and coordinate. We expect health care providers to specialize in order to perform tasks with a high degree of technical expertise and effectiveness, but we also need them to coordinate within and across their own settings in the health care space to maximize outcomes, including the patient’s experience of care. Up to this point, U.S. providers have generally done well in specializing and rather poorly in coordinating. Our payment mechanisms have likely fostered this environment. The dominant fee-for-service paradigm has engendered support for numerous specialized medical technologies and complex procedures but has failed to encourage care coordination across providers, settings and time.

Historically, the bottom line for health care organizations has not been affected by poor coordination. It is consumers (and payers) who have paid the price—both directly in terms of cost and indirectly in terms of hassle, wasted time and diminished outcomes. Given the extremely challenging prospect of redesigning organizational structures in health care to be more accommodating to patients, it is not surprising that most of the efforts thus far have simply tried to help patients deal with obstacles in the existing system. In other words, trying to make the best of what you’ve got. For example, “care managers,” “patient navigators” and other specialists have been brought in to help individual patients make their way through one or several episodes of care.

### **What Can Be Done to Make It Easier for Patients?**

To fully address patient navigation problems and their consequences, system-level interventions are needed. For example, at the medical appointment level, some have suggested having group appointments, which could expand and perhaps improve the time available to patients and providers for discussing conditions and treatments. Another model might be for medical teams to be constructed around patient needs, so that complex diagnoses or treatment issues could be fully discussed and decisions made with the benefit of having all relevant parties at the table.

Though not yet a reality, there are some examples of structural innovations that may facilitate patient navigation. Integrated delivery systems, which allow multiple health services to be managed by the same organizing entity, may improve coordination and ease patient navigation. This could be especially true in systems where health care coverage is integrated with delivery, such as Kaiser Permanente and Group Health of Puget Sound. Another idea being promoted to enhance patient navigation is the “focused factory,” which involves the reorganization of health care reimbursement and competition around care for particular health conditions, such as cancer and diabetes. This “one-stop shopping” model enables patients to get all the care they need in one place, so long as it is related to the particular condition. However, the most serious navigation, quality and cost problems frequently arise for patients with multiple conditions, not just one. Presumably, communication and information sharing between the various actors in these systems would be better, but we do not yet know whether this would translate into easier patient navigation. And while the creation of interdisciplinary teams has been cited as a possible solution and can lead to improved coordination and quality, there is no evidence to suggest that this would necessarily improve patient navigation, particularly given that teams do not follow patients through transitions of care from one setting to another.

### **What Does Navigation Mean to the Average Patient?**

Thus far, the health care system has assumed that with some guidance consumers will “figure it out” for themselves. Even to the savviest of consumers, however, this can be a daunting and often unpleasant task.

**Coverage Decisions:** At the outset, and assuming that they have a choice of coverage (and assuming they can afford one or more of the options), consumers need to select and figure out how to use a health plan. People getting coverage through employers or public payers can, to some extent, rely on those parties to provide some guidance, but people in the individual market are basically on their own. Even assuming that the volumes of forms and paperwork are written to be comprehended by a lay audience, there is considerable variation in people's abilities to understand the information and apply it to their own situation. Once a plan has been selected, patients still need to learn to use it to their advantage. This involves knowing what is covered at what level, following ground rules for using services (e.g., referral processes) and learning what to do in the case of a reimbursement dispute. For those in need of public assistance, another set of hurdles must be cleared just to prove eligibility for coverage.

#### **Health Care Service Decisions:**

Choosing the best health care services—and then using those services effectively—adds yet another set of potentially challenging tasks for consumers. Even a simple doctor's visit can pose a navigational challenge. Much emphasis is placed on the selection of a health care provider, and there is an ever-expanding body of information being disseminated to consumers in the hopes that they will select high-quality, low-cost providers. Yet the extent to which this choice is meaningful depends on whether providers are covered under the plans consumers choose, and are willing to accept new patients.

Once patients have successfully chosen providers, their navigational tasks are highly dependent on the level of health care services required to prevent or manage their illnesses. In addition to the emotional burden of illness, people challenged with major clinical events may have to assume an even greater responsibility for managing their own care. That may include learning about a variety of highly technical treatment options, working with providers to make appropriate treatment decisions, and ensuring that their care is being coordinated, since the system is not inherently

coordinated. For those managing multiple conditions over a long period of time, this workload is compounded, and the job of navigation becomes even more challenging.

#### **Facilitating Patient Navigation: Where We Are Now and Where We Need to Go**

Thus far, efforts to improve patient navigation have not challenged the existing care delivery structure; they have only introduced professional or lay “navigators” to assist patients within specific domains of care. In many of these instances, the role of the navigator is to 1) help patients access and use services, and 2) provide psychosocial support. This support function has been demonstrated to be a life-saving element of cancer care.

Health plans have used nurse navigators to manage complex conditions. Care managers and coordinators represent another version of this approach. Humana, for example, employs a set of trained nurses who initiate contact with beneficiaries whose diagnoses or service utilization patterns suggest a higher risk and/or cost. Though this practice is common, there is little evidence to suggest that it improves patient outcomes or facilitates patient navigation. Researchers looking at the use of navigators in cancer care suggest that these team members “differ from other cancer support personnel in their orientation toward flexible problem solving to overcome perceived barriers to care rather than the provision of a predefined set of services.” This suggests the need for further research to better understand the value proposition of such navigators.

Moving forward, it will be important to consider three primary questions in order to develop a research agenda that will help to better understand patient navigation: 1) Where should attention be focused? 2) Which patients should attention be focused on? 3) Which points in the health care sector should be areas of focus? With respect to the first question, given the role of the primary care provider as the de facto coordinator of care (whether it actually happens or not), it may be instructive to focus research in this area. Given the limited time and capacity of solo and small practice providers coupled with reimburse-

ment pressures, it may be best to start with larger, multispecialty groups. This would also afford the opportunity to explore navigation both within and between complex institutions.

Whatever settings are determined most appropriate for initial exploration, patient navigation researchers may wish to look for opportunities to piggyback on work that is going on in related areas, such as care coordination, transitions management and disease management. They may also wish to explore opportunities for introducing more patient-centered tools that can facilitate coordination and integration of care, such as personal health records.

These specifics aside, several priority issues for initial research have been suggested, including:

1. Using population surveys to develop a baseline “epidemiology” of patient navigation in order to better appreciate and enumerate all of the elements involved and to identify who is most affected by navigation issues, under what circumstances they are affected and how patients currently deal with system complexity
2. Conducting observational studies that look at different patient navigation interventions currently being used, as well as treatment settings with different levels of intended structural “integration” models to measure their effect on patient outcomes and experiences
3. Developing interventions at the systems level to re-engineer the health care sector so that it becomes more inherently navigable by consumers
4. Documenting the health and financial consequences associated with problems in patient navigation

While research in all of these issue areas would require significant work, we will not fully appreciate the societal cost associated with the status quo—nor the potential savings associated with evidence-based solutions—until we better understand navigation problems in U.S. health care.

#### **About the author**

Alison Rein is a Senior Associate with AcademyHealth.