

To successfully navigate the health care system, consumers need nonbiased, accurate information, as well as understanding and support. They need to understand their health care options and make good health care decisions in their unique circumstances. Patient advocacy services can meet these needs. Various health care patient advocacy programs are available through independent organizations, insurers, health plans, physicians, hospitals, provider groups and nonprofit organizations developed to help patients with specific illnesses such as cancer, Alzheimer's disease, obesity and others. The long-term goal of patient advocacy programs is to teach patients and their families how to be their own health care advocates.

What Is Patient Advocacy?

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Health care today is complex and sometimes confusing to consumers, payers and providers. All are negatively affected in one or more ways by the endless mazes that comprise our health care systems and programs.

Health care premiums and overall costs continue to rise. Many payers believe shifting more financial responsibility and decision making to consumers may have the desired effect of reducing costs. Unfortunately, many health care consumers are not prepared to make wise and informed health care decisions. Studies show that when more financial responsibility is shifted to consumers, health care

costs are reduced. However, shifting more financial responsibility to consumers does not have the desired effect of reducing unnecessary care or improving the appropriateness or *quality* of care.

Most healthy people pay little or no attention to either the cost or quality of medical care until they, a family member or other significant person in their lives either becomes acutely ill or is diagnosed with a chronic illness. Many people feel helpless and bewildered in these situations. Health care professionals, even physicians, often need help to feel empowered.

Independent (nonbiased), accurate in-

formation, understanding and support can make it possible for health care consumers to navigate the health care maze successfully. Some trustees and other payers, who understand the dilemma that their members or employees face, are purchasing patient advocacy programs to help consumers make better health care decisions. The long-term goal is to teach patients and their families how to be their own health care advocates.

Other employers and some individuals are purchasing programs that promise to do all the management. Just as these individuals hire stock managers, they look to private health care “concierge” programs to help manage their “health assets.” One program describes its services as “health asset management.” Often these programs are sold only to selected individuals and organizations, and costly initiation and annual fees make these programs out of reach for most people.

Americans are, by nature, entrepreneurial. The problems that individuals face in navigating the health care system show a need for services that could help patients effectively understand their health care options and make health care decisions consistent with their unique circumstances. Beginning in the 1990s, a multitude of vendors began to offer products that they labeled “patient advocacy” services. In addition, some firms and private physicians developed health “concierge” services.

This article describes the variety of health care patient advocacy programs available through various vendors, including independent organizations, insurers, health plans, physicians, hospitals, provider groups and nonprofit organizations developed to help patients with specific illnesses such as cancer or Alzheimer’s disease.

A Historical Perspective

More than three-fourths of U.S. adults have one physician whom they consider to be their primary physician, despite recent changes in the nation’s health care delivery systems. Unfortunately, surveys of primary care patients over the past 15 years reveal that despite long-term primary care relationships, the ideals of whole-person, integrated care are largely unmet in their experiences. Furthermore, the quality of

the primary care doctor-patient relationship has eroded over the past several years. —*Primary Care Assessment Survey (PCAS)*, Agency for Healthcare Research and Quality (HS08841 and HS09622).

The need for patient advocacy products and their market niche developed for many reasons, such as the complexity of the health care system, including the payment systems, and communications breakdowns. For example, many members covered under self-insured Taft-Hartley trusts do not know that the trust is the payer, that is, the insurance company. They believe the insurance company is the health plan that maintains and sells negotiated discounts obtained from its provider network. In addition, patients are becoming consumers: Many want to either have partnership with their physician and decision-making authority—or they want to take total control of their destiny.

Possibly the most significant factor in the development of patient advocacy, however, has been the breakdown in communications between physicians and their patients, often because of constraints on the amount of time physicians can spend with their patients. The importance of good communications between physicians (medical practitioners or healers) and their patients has been discussed since the time of the Greeks and Romans—before Hippocrates.

From early times through the 1960s and beyond, physicians have expressed concern about providing information to patients that could lead to losing hope of cure or improvement. Such loss of hope was viewed as possibly harmful, and some physicians were concerned that this could diminish physician status in the patient’s view.

Medicine, or the art of healing, has historically been tightly tied to religion and religious organizations. In the past, both physicians and patients viewed their relationships as sacrosanct: This meant that no one, including a patient advocate or even a family member, could be allowed to impinge upon the direct relationship between the physician and patient.

Even technological innovations were and still are viewed with concern for the doctor-patient relationship. For example, the French physician Rene Laennec invented the stethoscope in 1816. Laennec’s

contemporaries were concerned that the stethoscope removed the patient from direct physical contact with his or her physician, a process they called mediated auscultation. The stethoscope also allowed physicians to make more accurate diagnoses. Accurate diagnoses were not viewed favorably by some physicians because such diagnoses could rob patients of hope for recovery.

The stethoscope represented one of the first technological innovations in medicine. Although the reasons may be different, some providers often view new technologies in the 21st century with similar discomfort. New technologies are expensive. For example, one well-known cancer center recently opened a new state-of-the-art proton beam therapy center to treat aggressive cancers. The reported cost is approximately \$125 million. Most of the cost was paid by donations.

New technologies also mean physicians and staff need to learn how to *use* them. Lack of training and experience can add risk to any patient procedure or treatment. These concerns often prevent physicians from using new methods. A patient may be offered different types of diagnostic or treatment options depending on which physician he or she is assigned to or chooses within a medical group. Some physicians will tell patients that a new therapy is available but that a different physician will necessarily have to perform the procedure or administer the therapy.

If the technology or therapy is not available at the facilities where the physician is on staff, the patient may not be told about it. It is not unusual for physicians to be unaware of what competing systems offer. Some physicians, however, are adamant about keeping a given patient within his or her system. This can make it difficult for patients who want to go elsewhere. This underlines the need for patient advocacy.

What Is Patient Advocacy?

No one denies that navigating the health care system is difficult. The stated purpose of *patient advocacy* programs is to empower patients to work together,

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preferably in partnership with their physicians, to make informed decisions about diagnostic procedures, treatments and other care.

Many patients know that they cannot realistically expect their individual needs to be the top concern of their doctors, hospitals or their insurers. Rightly or wrongly, patients believe providers' and health plans' primary concern has become cost containment; they understand the need to contain spiraling health care costs. Most also recognize the constraints on physicians' abilities to spend time with them. But patients must have:

- Accurate, comprehensive, understandable and usable information about their condition and treatment options
- Identification of, and access to, the services that best meet their unique needs.

Patient advocacy is about empowering patients. But what does this mean? Empowered patients are informed about their conditions, the diagnostic and treatment options, and the risks and benefits of various treatments; they are able to make informed choices about treatments, medications, doctors, hospitals and locations for care. Empowerment also should include patients' ability to identify appropriate services, that is, services whose potential benefit exceeds the potential risk, wherever they are provided.

The Risks of Not Being an Informed Consumer

Patient advocacy has many facets. Helping patients understand their options so they can make informed choices is one of the most important roles. The patient advocate must also ensure that members understand the power of information to anticipate and prevent mistakes.

Recent media reports have made most people aware that health care providers make mistakes. Often, however, these problems are perceived as things that happen in other towns or cities—not our own hospitals. A large volume of medical literature documents the problems that physicians and others face in diagnosing and treating many conditions, and the mistakes that are made.

For example, a pathology report or other test may not be accurate. A radiologist who does not have access to clinical

material may misinterpret a radiograph. The treating physician reviews the report and not the radiograph. As a result, the patient is diagnosed inaccurately. Inaccurate diagnoses, of course, typically result in suboptimal or wrong treatments. The treatment may be totally ineffective or only partially adequate.

In other situations, patients are diagnosed too late for current treatments to provide a desirable result. Patients often delay seeking care. Sometimes there are diagnostic or treatment delays due to scheduling or related access problems. In

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some conditions, treatment delays mean that a curable or treatable disease becomes incurable.

Another problem is the lack of systematic feedback received by physicians, surgeons and other health care providers about their performance. Well-meaning physicians, surgeons, nurses and technologists may not have the necessary experience, training, instruments or other resources to skillfully perform the surgery or administer the treatment.

The Question of Effectiveness

Standard practice may not benefit a particular patient or any patient. Patient advocates must help members understand that the effectiveness and safety of many medical and surgical procedures in common practice today have never been validated in controlled clinical trials. In simple terms, this means that many diagnostic procedures or therapies are harmful.

Physicians do not always have the information they need to determine which existing medical treatments work best for specific groups of patients. For example, the probability that a patient who receives the standard recommended chemotherapy for his or her cancer has only a 40% to 60% probability of benefit. Cancer specialists at major research institutions are only beginning to unravel the mysteries surrounding why some patients' tumors respond to a given drug or treatment while others do not.

Such limited information is recognized as one of the most serious challenges to measuring and improving quality of care and reducing cost. It is very confusing to patients when physician experts disagree about the appropriateness, usefulness or effectiveness of screening and diagnostic tests, treatments and procedures. The patient advocate must be prepared to help the patient find the resources to successfully navigate these types of situations.

Patient Advocacy Program Objectives

Trustees who evaluate patient advocacy services for their covered members should begin with a plan describing what they want to achieve. The purpose and focus of patient advocacy programs are different from utilization management, case management and disease management programs (see the table). It is easy to confuse these programs.

Patient advocacy programs should be able to address the following objectives:

- Increase consumer awareness of health care resources and patient safety issues so patients feel empowered to play an active role in their health care.
- Encourage patient involvement in their health care. For example, patients should obtain copies of all their medical tests and question any results that they do not understand or which appear abnormal in any way. "No news" may not be "good news." Research shows that many doctors' offices do not have the necessary systems in place to ensure that patients are apprised about test results that require followup.
- Offer consumers tailored information and strategies to address their health

Differences Among Programs

Method/ Program	Utilization Management	Case Management	Disease Management	Patient Advocacy
Purpose	Decrease costs by reducing unnecessary use of medical services; uses explicit criteria to manage location of treatment and types of services and treatment that are believed to be “abused” by providers, i.e., used when not necessary.	Decrease costs by intervening in types of cases that are typically high cost (e.g., start to generate large claims) and often have an acute onset. Neurological (head) injury, transplant, etc., are often candidates.	Decrease costs by focusing on chronic conditions that become high cost over time such as diabetes, heart disease, end-stage renal disease and some cancers.	Improve the quality by helping the patient identify and access the right provider for the right diagnosis and the right treatment in a timely manner. Remove barriers to receiving the most effective care.
Origins	Negate financial incentive effects of fee-for-service medicine, i.e., physicians and hospitals tend to make more money when they perform more services.	Origins in disability management; the objective of early programs was to assist employees to return to work as soon as possible, i.e., reduce both direct and indirect costs.	Recognition that most at-risk patients, whose conditions later become high cost and acute, don't get effective treatment when their diseases are in a more chronic and manageable stage.	Quality can be improved and costs reduced by getting the right patient to the right provider for the right diagnosis and right treatment at the right time. Value = Quality ÷ Cost
Focus	Protection of the interests of the health care system and society as a whole by preserving resources.	Integrate and mobilize resources to meet individual patients' needs, which are generated by this acute episode of care.	Focus on “populations of patients” such as diabetics, patients with asthma to prevent costly exacerbations, such as hospitalizations, emergency room visits.	Assisting individual patients with chronic and acute conditions to understand their condition and their options; helping them remove barriers to receiving needed and desired care. Focus on preventing quality problems for high-risk diseases and populations.

Table

problems in terms of their health risks, family history, personal medical history, and the capabilities of physicians and hospitals to successfully treat these conditions.

- Help ensure quality care by providing patients and their families with the same level of knowledge, care and forethought that they can access in making other important decisions.
- Provide patients/members and their families with information about all facilities and professionals that offer innovative and successful treatments for their conditions.

- Help patients/members sort through the medical marketing “hype.”

Every day, the media describe new treatments that are on the horizon or that have recently been introduced into community practice. Some of these treatments have not been well tested; others are a distinct improvement over previous methods; and many will never be applied in humans because of the costs involved in testing or because they simply do not work.

Unfortunately, some of the improved treatments can be introduced by physicians and hospitals that have not had the necessary training. For example, min-

imally invasive surgery is gaining in popularity with patients. As anticipated, physicians are struggling to learn these techniques. Many patient complications and deaths have occurred because physicians perform these procedures on patients before they have received the recommended training and before they have the necessary experience under supervision.

To their credit, other hospitals approach new treatments cautiously until they are certain there is agreement on appropriate physician training, experience

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and protocols that describe when to apply specific procedures.

Health Care Information Needed

Health care strategies should include choice, information and identification of and access to proficient providers that meet unique consumer needs. Many different forms of information can and should be provided to patients and their families. For example:

- Information regarding the condition: what it is, special risk factors and risks for related conditions (For example, some diabetic patients may be at higher risk for colon cancer.)
- An overview of additional diagnostic modalities to determine how serious the condition is or whether the diagnosis is accurate and comprehensive
- An overview of treatment options (standard, investigational, experimental with definitions of each type) and information regarding who the best candidates for these treatments have been
- All indications and contraindications and prognostic information available regarding one or more hospital's experience with diagnosing the condition or offering treatments. For example, a physician that is primary author on several hundred papers that describe his or her own and his group's experience in treating prostate cancer patients is likely to be experienced. Indeed, some surgeons and physicians publish their group's survival and complication rates. This may be in a format that is easily understood by everyone or it may be described within professional publications.
- Information describing the institutions where treatment options are available. The immediate focus is often tertiary/quaternary centers in the patient's geographic area, but may also include information about treatment options outside of the immediate region.
- Information about special lodging and other travel amenities for patients and families is available through some centers for some conditions. (For some diseases and situations, low-cost or no-cost air travel is available.)

- Support for the patient and family as needed, including accompanying patients to doctor visits; facilitating referrals to other agencies that can provide support; working with social workers and other support personnel when patients need to travel to distant cities for care.

Types of Patient Advocacy Programs

Patient advocacy programs range from those that focus on specific diseases to those that are available only to specific populations. Each trust fund and pur-

Patient advocacy programs range from those that focus on specific diseases to those that are available only to specific populations. Each trust fund and purchaser group has unique needs.

chaser group has unique needs. At minimum, a patient advocacy program should be able to provide the following:

- Tailored, reliable information on health risks or medical conditions
- Information on experienced, proficient providers who can ensure access to optimal treatments
- Location of physicians and hospitals that have the special expertise and resources to diagnose, treat and manage rare disorders
- Assurance that necessary testing has been performed to produce complete and accurate diagnoses
- Assurance that all available and appropriate treatment options have been fully explained and understood
- Access to evaluations of new technologies to help patients make informed choices
- Empowerment of patients to carry

out their own critical role as partners in managing their conditions

- Facilitation of open communications between patients and their physicians
- Explanation of coverage denial and the technical assistance necessary to appeal decisions
- Resources available from other advocacy organizations, such as those that offer financial help to patients with specific conditions.

Evaluating Patient Advocacy Services

Although many programs look alike on the surface and their marketing materials may imply they provide similar services, these services may actually be very different. Differences include the following:

- *Background of the program.* Some vendors have simply renamed their case management, disease management or utilization/resource management services as "patient advocacy." The table shows differences in the purpose, origins and focus of the various types of programs that are sometimes confused with each other.
- *Scope of services.* Services may range from providing information about benefits, helping patients understand their condition, assisting patients with understanding their pathology or other diagnostic report, accompanying patients to appointments via telephone or in person, helping arrange transportation and lodging for patients when needed, identifying the most experienced providers for specific diseases, etc.
- *Comprehensiveness and depth of services*
- *Individualized services.* Services can be tailored to meet the needs of individual patients.
- *Independence* from or (conversely) dependence on a payer that has objectives that may conflict with (or conversely, coincide with) those of the patient
- *Goals, culture and history of the program vendor.* For example, is this a totally new approach for the vendor, or a natural extension of existing philosophies and services?
- *Educational requirements for individuals providing the services.* For example, how knowledgeable are staff

about the provider community and quality assessment?

- *How quality care is defined and assessed.* Is *quality* defined as meeting the patients' needs and expectations without deviation—or is the primary customer a specific group of providers seeking more business or to lower health care costs?
- *Limitations on information provided to consumers.* For example, is it permissible for staff that interact with patients to provide all available public information about a provider organization, specific physicians, differences in diagnostic procedures and treatments available at any or all facilities?
- *Organizational culture.* Who is the real customer for the product? Is the program totally focused on patients, or is the program's primary emphasis on accomplishing some organizational or payer goal?

All of the above are important factors to consider. For example, some health plans will offer patient advocacy services to help patients understand benefit questions and locate “appropriate” providers within the health plan network. Consumers benefit most if the patient advocacy firm's primary customer is the patient.

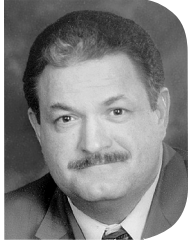
One size does not fit all. Trustees should ensure that the patient advocacy organization they select has the flexibility, resources and willingness to meet the unique needs of individual members and their families.

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