

# Patient Empowerment -- A Trend that Matters

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by Robert B. Bruegel, PhD

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*Increased patient empowerment will generate an extensive shift in fundamental roles and procedures in healthcare, including the roles of HIM professionals. Here's a look at factors influencing patient empowerment and a forecast of how patient and provider communications are likely to be affected in the future.*

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As the effective management of patient information becomes a critical necessity for all healthcare organizations, it is not surprising that the amount of interest, attention, and investment devoted to electronic health information systems also continues to increase. What is less apparent is the extent to which many of the same social, economic, and technological forces behind the changes in the organization and financing of healthcare -- and thus the increasing interest in electronic health information systems -- are also linked to increasing demands for "patient empowerment." In this context, patient empowerment can be defined as the increasing ability of patients to actively understand, participate in, and influence their health status.

## Patients as a New Customer for HIM Professionals

Because patient empowerment centers around access to health information, the changes that result from patient empowerment will directly affect health information management professionals. In its strong form, patient empowerment will introduce an entirely new customer -- the patient -- into the work of HIM professionals. The demands that this new "customer" will make are likely to conflict with the demands being made by the current "customers," such as existing health organizations, insurance companies, government agencies, or health providers. To make all of this more interesting, while HIM professionals are dealing with increasing patient demands for access to health information -- including direct access to both their printed and electronic medical record -- there is likely to be a substantial increase in overall concerns about the privacy and confidentiality of health information.

## Great Expectations: Factors Leading to a Rising Demand for Patient Empowerment

A number of factors are generating more demands by patients for an increasing role, involvement, and say in their healthcare and health status. These include:

### Increase in Overall Consumer Empowerment

Consumers at all levels now tend to demand more say and information in all aspects of their relationships with external organizations -- government, schools, or the healthcare system.

### Shift to Chronic Disease

Increasingly, more emphasis is being placed on chronic, as opposed to acute, disease, a result of the convergence of medical technologies and the health demographic impacts of an aging population.

### Impacts of Cost Containment

Employees are being asked to pay for a significant portion of their health insurance costs, and they are increasingly asked to share a portion of economic risk through such devices as medical savings accounts. At the same time, they find their choice of providers and treatments restricted under many forms of managed care.

## **Increase in the Availability of Health Information**

Health information is increasingly available to consumers -- whether in print media, broadcast television, or online through the Internet.

## **Incentives for Patient Education with Managed Care**

The rapid growth of managed care operating under capitation creates major financial incentives to promote patient involvement and education.

## **Move to Larger Systems of Healthcare**

Increasingly large systems of care are evolving, in which patient care is increasingly provided by a rotating team of providers, rather than individual providers giving continuous care to individual patients.

## **Continuing Legal Exposure**

While medical providers have long-standing and clear duties to educate patients, obtain their informed consent, and warn them of potential problems and consequences of all aspects of their healthcare, these obligations are now being extended to healthcare organizations -- leading to an organizational recognition of the importance of involvement and participation in the healthcare process by patients.

As computers become more powerful and at the same time cheaper -- and as the amount and breadth of information available to business and consumers continues to rapidly increase -- the amount of information technology (and information processing capability) generally available will get to the point where patients will stop "being patient" and will insist on being full partners in the provision of healthcare. This is likely to include not only complete, full, and direct access to all medical record information, but also the right to review, comment, and insert information into their records -- all in a context of greatly heightened awareness, concern, and legal exposure for any and all violations of privacy and confidentiality.

While the trend toward patient empowerment is still in its early stages, several broad aspects of the trend are becoming clear. These include:

## **Access to External Sources of Information**

Patients increasingly have access to significant sources of healthcare information -- as use of the Internet increases, this already significant trend will accelerate.

## **Expectations for Customer Service**

Customers will clearly begin to ask (if they haven't already) "If it is possible for hotel chains and airlines to capture and understand my preferences for an aisle seat or a nonsmoking room, why can't my health network do the same?" As the "easy" part of cost reduction in healthcare is completed, customer service will likely become more of an issue. Successful health networks will soon spend as much time and money as political candidates on polling and patient satisfaction. This process has already begun with many large managed care organizations.

## **Transparent Practice**

Deployment of electronic information systems will greatly increase access to detailed information on health practices. As this information becomes available -- and becomes critical to the survival and success of health providers and networks -- the availability of the initial information will likely generate an increasing demand for even more extensive information systems -- which in turn will make it possible to expect (and demand) even more information. A critical step in this process will be the development of a new generation of health vocabulary systems that will enable patient information to be shared across systems and will enable patients to do increasingly sophisticated reviews on the record of their care.

As the richness of available information increases, patients and employers will increasingly expect access to information. While the number of patients making these demands will be small initially, these early empowered patients will have an impact far beyond their numbers.

### **Continuity of Information from Point of Care to the Internet Home Page**

As more information becomes available to empowered patients, the consistency of information provided by healthcare organizations will become increasingly important. Other aspects of information services made available to the clients of healthcare organizations will need to be made consistent with the most significant aspect of patient education information -- namely, that provided at the point of patient care and reinforced by physician-patient contact and face-to-face teaching. Patient information provided by various parts of the health network, such as telephone counseling/demand management services or through the organization's home page on the Internet, should be consistent with that provided at the point of care.

### **Electronic Interaction with Both Providers and the Electronic Record**

We are just beginning to understand what it will mean to integrate patients into an overall healthcare information system. Over time, however, it is likely that information professionals who use e-mail and the Internet in their work lives will press to use the same information tools in their healthcare -- exchanging e-mail with health providers, reviewing and correcting their electronic patient record, and communicating with networks of other providers and other clients with similar health problems. Even this first stage will create a significant number of issues for the design, implementation, and ongoing operations of CPR systems, including a new set of security and confidentiality concerns -- for example, how to maintain system integrity while allowing outside access -- as well as issues such as how e-mail messages between the patient and provider should be incorporated in the patient record.

It is important to understand that providing electronic access to the patient record will have significant impacts on the overall organization and process of healthcare, since it will allow the patient to take time both before and after any actual encounter with the health system to examine, review, and consider the care that was provided.

### **Remote Monitoring**

As bandwidth to the home increases, it is likely that there will be a rapid increase in remote monitoring of health status. Data from such remote monitoring, coupled with patients' other observations of their condition, will need to be incorporated in the computerized patient record. Such monitoring will not occur in a vacuum; it will need to be accompanied by additional communication, training, and information support. This in turn will pose significant new demands on electronic health information systems, which are still struggling to simply capture and incorporate data streams from various devices and test equipment within health facilities into the electronic patient record.

### **Community Linkage**

Celebration, the neo-traditional community currently being developed just south of Walt Disney World in Orlando, FL, is currently serving as a model for the future technical linkage between health facilities and members of the community. Homes in Celebration are equipped with high-speed fiber-optic connections; it is envisioned that this will be used to provide a broadband, interactive link between the homes and local and worldwide health facilities and information resources. Similar projects are also being developed in a number of other sites, most recently Jacksonville, FL, in conjunction with the Mayo Clinic. Significant efforts in community-based education and empowerment are also being tested in Boise, ID, as part of a community health project sponsored by the Robert Wood Johnson Foundation.

### **Electronic Health Information as Communication Systems**

The main purpose of electronic health information technologies, from the point of view of patient empowerment, is communication. From this perspective, to better understand the impacts of increasing patient empowerment on health information systems and the role of health information management professionals, it is useful to look at the impact of patient empowerment in terms of communication among physicians, nurses, ancillary providers, patients, and patients' families. This approach provides a way to systematically work through the implications of new information technologies in health systems

and organizations.

### **Provider-to-Provider Communications**

As more patient care is directed out of expensive inpatient facilities to the home, the electronic communication of patient status, orders, and other information among various health providers will become increasingly important. As patients become aware that most of such provider-to-provider communication takes place via e-mail, they are likely to ask to be copied on such communications and decide to actively participate in such communication by sending their own e-mail. This will be especially important if family members in other locations, particularly children of older patients, are included in the communication system. This will not only change the dynamics of these communications but will require new ways of incorporating communication from patients and family members into the record of care.

### **Provider to Patient/Family**

This is likely to take the form of general patient information generated either by the physician or under the direction of the physician and supplemented by specific messages to the patient from the rest of the care team (with responses and additional questions from the patient) as well as communication from the care team to the patient's family members.

From the perspective of patient empowerment, the most interesting paths are those that indicate communication going from the patient and the patient's family to members of the healthcare team, whether physicians, nurses, or ancillary providers, as well as communications going from the patient to other patients and from families to both patient and other families.

### **Patients to Providers/Families to Providers**

As patients increasingly join the communication stream with regard to their health, particularly as this occurs in a non-real time environment (as with e-mail), many of the barriers that have limited patient involvement and empowerment will disappear. Given extra time to look up vocabulary and to check additional resources, those patients who are motivated will begin to compose very powerful, well thought-out e-mail questions and responses.

As patients come to realize that providers are extremely busy, they will also realize that the information in their medical record, not the information in their personal physician's head, is now the basis for the consistency and quality of their care, and that if they want that care to be provided properly, correct record information is critical. As this awareness builds, patients' concerns with access to their records -- and the ability to not only correct but to add what they feel is pertinent information -- will rapidly increase.

### **Patients/Families to Patients/Families**

If, under managed care and capitation, patients come to perceive that providers no longer have an incentive to spend time with them, they are likely to turn increasingly to those groups that they perceive are highly motivated and responsive. Core among these will be self-help groups and other peer relationships.

## **Consequences/Opportunities of the Coming Shift to Patient Empowerment**

It is increasingly likely, therefore, that well before the end of next decade we will see the end of the traditional doctor-patient relationship based on the authority of the physician. Some believe that the traditional physician-patient model will be replaced by a model of centralized, bureaucratic control (by various combinations of insurance companies, government, and managed healthcare organizations) over both physicians and patients. But the explosion of information technology is making it increasingly likely that the outcome will be one of patient empowerment -- a situation in which patients are increasingly knowledgeable and demanding clients -- and where their preferences, concerns, and choices play an increasing role at every level of healthcare decision making.

In this scenario, there will be increasing consequences for healthcare networks, health providers, and HIM professionals. Patient empowerment will be especially important to electronic information systems, since electronic access to information will be seen as a key to enabling and effecting increased patient empowerment. The openness of various electronic systems and

their ability to support patient empowerment rather than become overwhelmed by it will thus become increasingly critical to the relative success of different electronic healthcare information systems.

At a minimum, electronic health information systems that can support the increasing demand for patient involvement must have the design flexibility to adjust to new care processes and the incorporation of new views of their data, as well as the ability to link to and utilize a broad additional range of patient information systems. These systems will furthermore require the development of entirely new support systems, such as the development of new clinical vocabularies that can document this broad range of encounters.

Given the rapid transformation of healthcare, most healthcare organizations are facing the need to invest in the electronic information systems required to survive in a managed care environment. This is a difficult decision, made even harder by the fact that with a few notable exceptions, most present and planned information systems have been designed to automate existing models of the process of healthcare that increasing patient empowerment will make cumbersome, if not actually obsolete.

One way of recognizing the stage of any group's empowerment is when the group stops asking permission and simply starts exercising increasing power. In many ways, this has already begun to occur with regard to the empowerment of patients throughout healthcare. As this process accelerates, understanding and anticipating the emergence of this new paradigm will quickly become a key requirement for designers and developers of electronic healthcare information systems -- and for those HIM professionals who are faced with the difficult decision not only of selecting which electronic health information systems to install but the even bigger and more challenging task of making such systems work in the new world that patient empowerment is likely to create.

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**Robert Bruegel** is president of *The Health Language Center*, a nonprofit organization whose charter is to develop the next generation of clinical vocabularies designed to support major trends in healthcare such as patient empowerment.

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