

2

PatientSite: Patient-Centered Communication, Services, and Access to Information

DANIEL Z. SANDS AND JOHN D. HALAMKA

Healthcare providers are not meeting the needs of online consumers. Over half the U.S. population is currently online and the place they turn for health information, after their doctors, is the Internet¹ (Fig. 2.1). In another survey, Internet users were almost as likely to turn to the Internet for healthcare information as they were their physician.²

Although 45% of online consumers would like to communicate with their physicians using e-mail, only 6% have done so.¹ Similar proportions of people have and would like to access a provider Web site (Fig. 2.2). Moreover, almost half of consumers who would like to do so would be willing to switch providers to find one who offered these services.¹ The proportion of those who have gone online to look for health information is 66% to 78% of those who have used the Internet, and that number is growing annually.^{2,3}

Online health consumers want the same kind of convenience they expect from other businesses today. They want to be able to communicate by e-mail, get information, and conduct transactions conveniently. In surveys, consumers consistently tell us the types of things they would like to do online: consult with their physicians about medical issues, refill their prescriptions, make appointments, look up their test results, and find information about health problems.^{1,4}

Healthcare Consumer Needs

Communication

Although there are many channels available for patient-provider communication, including in-person interaction, telephone, fax, and page, patient-provider interactions are generally restricted to appointments and telephone calls. Because both of these are synchronous communication channels, busy patients and overbooked providers have difficulty making contact. As most of the world gravitates toward asynchronous electronic communication for nonurgent communication, it seems clear that electronic patient-centered com-

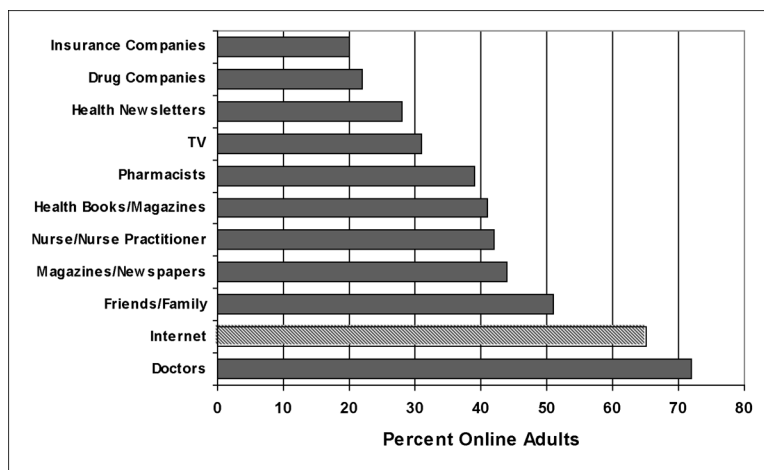


FIGURE 2.1. Sources consumers use for health information. (From Manhattan Research, LLC. Reprinted with permission.)

munication such as e-mail would be useful in patient-provider interactions. Unfortunately, although half the U.S. population uses e-mail, only about 25% of physicians have used e-mail to communicate with their patients⁵ and probably only 10% to 15% use it regularly.

E-mail has a number of beneficial characteristics when used according to a set of guidelines.⁶ The asynchronous nature of e-mail allows users to send and read message at their convenience. Unlike telephone calls, which courtesy dictates cannot be used outside of certain hours, one may communicate electronically any time of the day or night. Also, instead of a rushed telephone

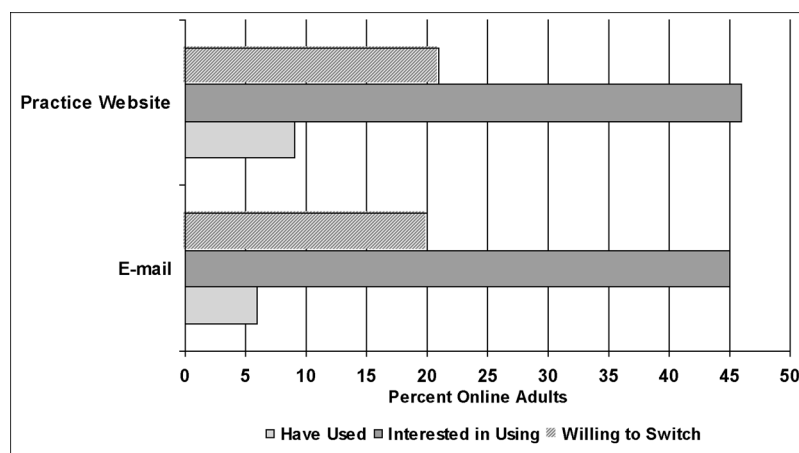


FIGURE 2.2. Consumer demand for practice Web site and physician e-mail. (From Manhattan Research, LLC. Reprinted with permission.)

conversation or brief appointment, patients may take their time composing their questions, and physicians can do research before responding. In addition, unlike telephone conversations, which are often not documented adequately in the patient record, e-mail is self-documenting, providing a convenient transcript of the interaction that can be filed in the patient's record. This also permits patients to reflect on their providers' comments and discuss them with friends and family members. In contrast to an appointment, e-mail communication is informal, most akin to a telephone call. Using e-mail improves communication between patients and their providers and increases patient satisfaction.

However, e-mail has some drawbacks when used for electronic patient-centered communication. For one thing, because e-mail has no linkage to the record of the patient with whom the discussion is taking place, it is both cumbersome to archive and difficult to determine the context of a patient's question (one must correctly determine the patient's identity and pull the record). Another issue is that messages are typically unstructured, and this may reduce the efficiency of communication. Also, in many practices, patients can send e-mail only to their physician rather than to other persons in the practice. This means that the physician must triage all incoming messages himself and deliver them to the appropriate person(s) in the practice. Finally, e-mail as generally used is an insecure channel of communication; messages can be read inadvertently or intentionally by third parties. It is this last issue that some fear may make clinical use of unencrypted e-mail a violation of the Health Insurance Portability and Accountability Act (HIPAA).

Information

It is clear that patients who use the Internet want access to health information. For most of the history of medicine, health information has been the exclusive province of the medical practitioner. This information asymmetry, where the physician knows everything and the patient knows nothing, has been a source of comfort to physicians, but is contradictory to the free flow of information that the Internet has brought about. Health information is available through tens of thousands of Web sites, many of which have reliable information. Patients want to learn about health promotion, medical conditions, and treatments.¹

Patient also want access to their medical records, medications, allergies, problem lists, appointment history, and even their test results. HIPAA requires that we let patients view their medical records, but it's still a quite cumbersome process in most institutions. If patients have better access to information, they can be more active participants in their health.

Convenience

Most people who use the Web are accustomed to online "convenience" transactions, such as ordering airline tickets, contacting customer support, and

ordering or returning merchandise. In health care, we offer almost none of these conveniences to our customers. Patients who need prescription refills, appointments, managed care referrals, or answers to a billing question, or who need to update their contact information must negotiate these tasks through telephone calls. This leads to patient frustration and inefficiency on both ends of the conversation. Clearly, we can offer better service, and patients have a right to expect these services to be available online.

By recognizing the needs of online healthcare consumers, healthcare institutions can work to meet them. In 1999 at CareGroup Healthcare System, we initiated a project to address these issues.

CareGroup and Beth Israel Deaconess Medical Center

CareGroup Healthcare System is an integrated healthcare delivery system based in Boston, Massachusetts. It comprises five hospitals (including the flagship, Beth Israel Deaconess Medical Center) and 1700 medical staff who provide care for more than one million patients through many affiliated practices. CareGroup has been at the forefront of technologic innovation in health care since it implemented one of the world's first clinical computing systems, the CCC system, a quarter-century ago,^{7,8} and the online medical record in 1989.⁹ The CCC system also contained one of the first e-mail systems to be used in a clinical facility. CareGroup was named the most technologically advanced healthcare company in America by Information Week magazine.

Beth Israel Deaconess Medical Center has a legacy of patient-centered care. In the 1970s we did trials of interviewing patients using computers¹⁰ and early experiments of giving patients their medical records to bring to their appointments.¹¹ Beth Israel was also the home of one of the first divisions of academic general internal medicine.¹² In the 1980s the primary nursing movement and other nursing care innovations were implemented at Beth Israel.¹³ Beth Israel Hospital began a program, funded by the Picker/Commonwealth Patient-Centered Care program, to survey patients about their healthcare experiences.¹⁴ In the 1990s, we started a patient-family learning center¹⁵ for patients, their caregivers, and the general public. One of the authors (D.Z.S.), who practices medicine at Beth Israel Deaconess Medical Center, had been actively promoting the use of e-mail in patient care through policy and educational efforts at the national level.

The PatientSite Project¹⁶

In 1999 members of the CareGroup information system (IS) and Beth Israel Deaconess Medical Center's Division of General Medicine began discussing how to best involve patients in their care and meet the needs of online patients. As elements of this, we wanted to allow patients to see their records

online and communicate securely with their healthcare providers. We decided that the best way to do this was through a Web site using secure sockets layer (SSL) encryption.

To execute this, the group initially met with an outside company to do the programming, but we later realized that it would be more efficient to do the programming internally. We developed this using Microsoft Internet Information Server, Microsoft SQL database, and active server pages with server-side scripting to maintain client platform independence. Displaying the patient record information from the CCC system through a Web browser was done using technology developed by one of the authors (J.D.H.) in a project called CareWeb.¹⁷

In April 2000 we began registering physicians, staff, and patients in a single practice. We gradually added a small number of other CareGroup practices, physicians, and patients. By August 2000 we had more than 1000 patients online, as well as 43 physicians in 10 practices. We declared the pilot a success and moved to wider deployment. As of February 2003 we had 120 physicians in 40 practices using PatientSite and had enrolled 11,000 patients.

Design and Implementation Considerations

We wanted to build PatientSite using standard tools. This included the server software, programming language, database, and security tools. We wanted to strike a balance between usability and security, recognizing that a system that was too well protected would require trade-offs of usability. Physicians would need to endure an extra layer of security, however, because they would have access to personal information from all of their patients, whereas patients would have access only to information about themselves.

At the time we developed PatientSite, there were many types of Web browsers in common use, so we utilized mainly server-side scripting to maintain browser independence. This imposed serious limitations in our user interface design. Later, Microsoft's Internet Explorer became the most commonly used browser. We in turn conformed to the capabilities of Internet Explorer, which afforded us more flexibility in user interface design.

From an implementation standpoint, we wanted users to initiate the registration process online and then complete the process through a telephone interaction. We considered requiring personal contact to register patients, but so as not to impede the registration process, we discarded this in favor of allowing the confirmation to take place via telephone.

We wanted to enable physicians to control how PatientSite worked for them. For example, we felt that physicians should decide which features of PatientSite their patient could use and how their messages should be routed.

Security

PatientSite is a secure Web site that uses SSL with 128-bit encryption. Users access it by logging in with a user name and password. We considered some of

the advanced security used in the Patient-Centered Access to Secure Systems Online (PCASSO) project,¹⁸ but felt that a complicated multistep log-in procedure would be too cumbersome for wide deployment among physicians and patients. After all, many of these same patients had been using unencrypted e-mail to discuss medical issues; a password-protected secure Web site provided protection well beyond that. For physicians we did require a second layer of authentication, for which we initially used SecureID.¹⁹ This was an expensive technology to use and support, however, and was prone to failure; two thirds of the log-in attempts were unsuccessful, and managing the hardware tokens proved problematic. We later settled on using physicians' clinical information system log-in IDs as the secondary authentication mechanism.

Secure Communication

One of the features of PatientSite is secure messaging. Users (patients, staff, and providers) have a mailbox on PatientSite that allows them to send messages to other users on PatientSite. No clinical information ever leaves the secure Web site. When a message arrives, recipients are alerted via an unencrypted e-mail message sent through regular e-mail. Recipients can then click on the PatientSite URL, their Web browser will open, and they can log in to read their message.

The functions of the PatientSite mailbox are in many ways similar to those of an ordinary e-mail program. Each message has a subject and a body. Messages can be composed, read, sent, and forwarded to others. Other features differ from e-mail. Each message has a classification, such as "clinical," "referral," and "prescription." Because messages have a classification, they can be automatically routed to those who can best handle them (e.g., prescription requests to the prescription staff). We allowed physicians to dictate routing of these various message types. By default, clinical messages would be handled directly by the physician.

Services for Patients

In addition to secure messaging, PatientSite allows patients to perform "convenience" transactions online. This includes requesting appointments, obtaining prescription renewals, requesting managed-care referrals, and viewing their bills.

Patients wishing to have a nonurgent appointment may (if their physician has permitted it) view the physicians schedule and fill out a Web-based form specifying when they would like the appointment. We considered permitting patients to actually book themselves into their physicians' schedules, but we felt that booking a medical appointment online is not the same, for example, as buying airline tickets online; it requires human intervention to make sure the scheduling is appropriate based on physician, patient, and scheduling factors. The appointment request is sent and reviewed by whomever the physician has designated as being responsible for managing these requests. The patient is

Prescription Request
[Menu]

Enter Your Medication Information

Provider: Ives, David MD (clinician) Request: Call it in to my pharmacy

Medication: Strength:

How often: Quantity:

Enter your callback number and any comments

Phone: (617) 222-1515 Comments:

Enter Your Pharmacy Information

Pharmacy: cvs Search

Address: South Main Street

City: Sharon State: Zip: 02067

Phone: 7817849928

Submit

FIGURE 2.3. PatientSite prescription request.

contacted either through secure messaging or by telephone to complete the booking.

PatientSite similarly allows patients to request prescription renewals using online forms. In this case, the patient specifies not only details about the prescription but also delivery instructions for the prescription. Prescription information is automatically completed when the patient uses the refill button next to a medication on the medication list screen (Fig. 2.3). The prescription can be left for the patient to pick up, or the patient can specify that the prescription should be mailed to them or should be called in to a specific pharmacy. Each patient's favorite pharmacy is the default, but other pharmacy information may be entered; a pharmacy lookup is provided as a reference. In addition, when patients need specialty referrals, online referral forms enable them to request the referral from their primary care physician.

All of these requests generate a message on PatientSite. While many of them can be processed by support staff without physician involvement (if the physician has designated others in the office to handle them), the messages may be routed back to the physician if there are questions about them. Prescriptions sometimes require a physician's signature, as do managed-care referrals.

We also enable patients to view their bills online, something only possible if the patient's physician uses our centralized billing system.

Physicians can control both the handling of messages and whether to enable patients to request prescription refills, appointments, and managed-care referrals or to view their schedule.

Patient Education

Every patient's "home page" on PatientSite contains customizable health education links (Fig. 2.4). These may be "prescribed" or suggested to a patient by a physician through a message (often to support a response to the patient) or they may be selected directly by the patient. Discrete links may be added, but patients can also select predefined collections of links, clustered by category. These collections are managed by our patient education committee.

Patients may also view drug information monographs about each of their drugs by clicking on the drug of interest that appears on their medication list. In this way they can better understand their medications, how to take them, and what adverse effects can result.

Integration with Record

All patients registered on PatientSite have links to their records that are established at the time of registration. Once this is done, it is possible for patients to view their records online. Patients may see most aspects of their record online, including medication lists, problem lists, allergies, and all test results (except initial HIV test results). If the patient's physician does not use computerized patient records or does not have tests performed through one of our affiliated medical centers, these elements will not be viewable.

We wish to emulate best practice with respect to storing online communication. Therefore, clinicians can view all messages sent through PatientSite through a "Messages" section of the clinical information system. All PatientSite messages are archived as long as the rest of our clinical information.



FIGURE 2.4. Patient home page on PatientSite showing health education links.

Personal Health Record

Patients can maintain their own record on PatientSite. They can record their own medications, problems, allergies, and notes. They can also track and graph data over time, such as blood glucose measurements, weights, blood pressure, symptom scores, and other quantitative information. Finally, they can upload files, including images, documents, and spreadsheets.

Results

Since the implementation of PatientSite in April 2000, we have monitored its use both by patients and providers. Figure 2.5 shows the enrollment over time of patients and physicians in PatientSite. We counted as active users only the patients who logged on and electronically signed the usage agreement after they were enrolled.

As of February 2003 PatientSite had 11,103 active patients, defined as patients who had logged on at least once after they had been registered. The median age was 43, with 4% over the age of 70; 57% were female.

The 121 attending physicians came from 40 different CareGroup practices. In addition to several primary care practices, PatientSite physicians came from a number of different specialty practices, including allergy, cardiology, hematology-oncology, nephrology, obstetrics-gynecology, and pulmonology. There are also 225 support staff registered on PatientSite, such as secretarial, nursing, and appointment staff.

As of this writing, we have begun to register nonphysician clinicians on PatientSite, including nurse-midwives and nurse practitioners. We are in the planning stages of enrolling residents.

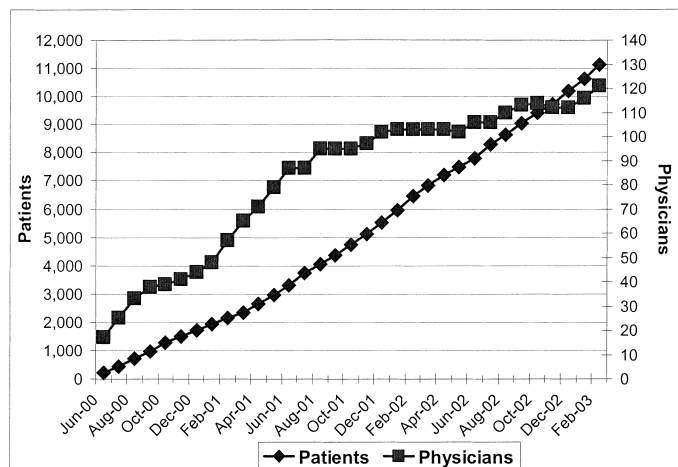


FIGURE 2.5. Active users of PatientSite.

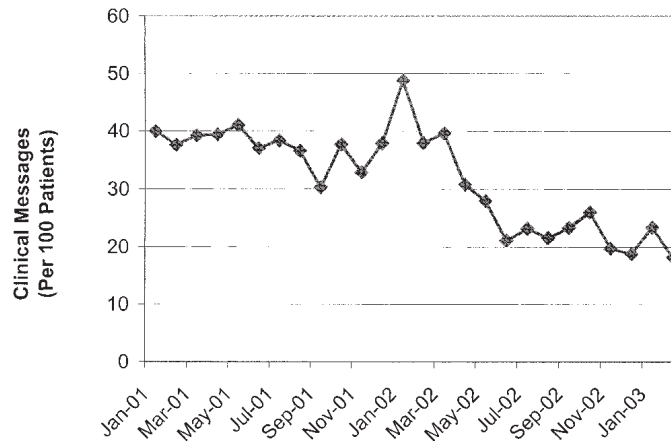


FIGURE 2.6. Clinical messages over time.

One of the ways to show a system is useful is to show that it is used over time by voluntary users^{7, 8, 20, 21} We also wanted to begin to understand the work flow implications of this new communication medium. We therefore examined the volume of messages sent each month over time. We broke the messages down by type, since different messages are handled by different members of the practices. For example, clinical messages are almost always sent directly to physicians, while prescription requests are generally handled by nonphysician staff.

Since the message volume would be proportional to the volume of users, we adjusted the monthly message volume by dividing by the number of users and multiplying that by 100 to give message volume per 100 patients over time. The adjusted clinical message volume is depicted in Figure 2.6, and the nonclinical volume is shown in Figure 2.7.

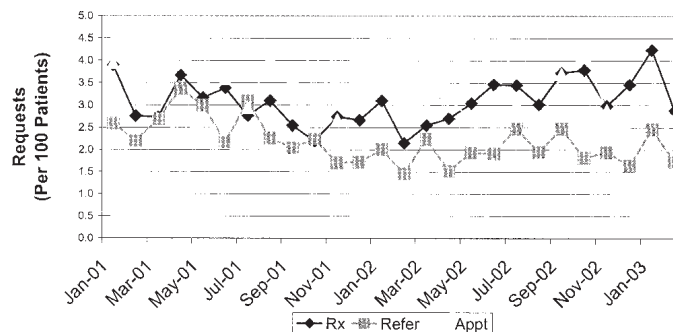


FIGURE 2.7. Administrative requests over time (prescription, referral, and appointment request).

We also examined patients' behavior in looking at their clinical record online. Every month, 16% of registered patients look at their record through PatientSite.

Discussion

Patients cannot register for PatientSite unless they have a physician who uses PatientSite. Once we enroll a physician, all of the physician's patients become eligible to use PatientSite. Since patients usually find out about PatientSite when they come to the office, the patients accrue gradually over time. Because of this, even if we stopped registering new physicians (which happened near the end of 2002 as we were doing a major system upgrade), we would continue to add new patients until we exhausted the panels of the registered physicians.

One of the things that worries physicians about electronic communication is that they will be flooded with e-mail. Our data do not support this concern. Looking at the volume of clinical messages, we see that the number of messages handled by physicians is quite modest, on the order of 20 to 40 messages per month per 100 patients. If we imagine a busy practitioner who has 1500 patients using PatientSite, the maximum number of messages he can expect to handle from patients each day would be 15.

Even as it has been well received by many patients and physicians, PatientSite has raised controversial issues that are worthy of future discussion:

- Should patients have full electronic access to their record? Should certain types of data be restricted? Is it necessary for physicians to review results before patients can view them?
- How should information from the medical record be presented to patients to enhance their understanding of their health without needlessly alarming them?
- PatientSite has three major stakeholder groups: patients, physicians, and practices. How can we best balance the needs and concerns of each group to guide development?
- Should patients be permitted to use PatientSite to view their record if their physician does not use PatientSite?
- For patients with more than one physician using PatientSite, how do we incorporate all the physicians' preferences about patient access to information?
- What should happen to patient-entered information in the personal health record? Should physicians be able to view the patient's personal health record? Should they be required to do so?
- In a teaching environment, how should preceptors oversee their trainees' use of electronic messaging with patients?
- Is it fair to offer a service like PatientSite to Internet-enabled patients without enhancing service for patients who cannot use the Internet?

- Should physicians be reimbursed for using PatientSite? If so, who should pay? How much should they be reimbursed?
- How can healthcare organizations justify the cost of projects like PatientSite?

Conclusion

Online health consumers are increasingly prevalent and are therefore important to healthcare providers. Organizations must fulfill their needs for communication, information, convenience, and access to their health records. PatientSite is an excellent way to meet these needs. Both patients and providers have vigorously adopted it, yet the demand on physician time is modest. The system has introduced controversial and interesting issues that we continue to work through. PatientSite is also a useful platform for future projects, such as patient-computer interviewing, disease management, healthcare quality, and patient safety.

PatientSite can be accessed at <https://patientsite.bidmc.harvard.edu>.

References

1. Manhattan Research, LLC. CyberCitizen Health v2.0. New York: Manhattan Research, 2002.
2. Horrigan JB, Rainie L. Counting on the Internet. Washington, DC: Pew Internet and American Life Project, December 2002.
3. Harris Interactive. No significant change in the number of “cyber-chondriacs”—those who go online for health care information. *Health Care News* 2003;3:4.
4. Harris Interactive. Patient/physician online communication: many patients want it, would pay for it, and it would influence their choice of doctors and health plans. *Health Care News* 2002;2:8.
5. Manhattan Research, LLC. Taking the Pulse v2.0. New York: Manhattan Research, 2002.
6. Kane B, Sands DZ for the AMIA Internet Working Group, Task Force on Guidelines for the Use of Clinic-Patient Electronic Mail. Guidelines for the clinical use of electronic mail with patients. *J Am Med Inform Assoc* 1998;5:104–111.
7. Bleich HL, Beckley RF, Horowitz G, et al. Clinical computing in a teaching hospital. *N Engl J Med* 1985;312:756–764.
8. Safran C, Slack WV, Bleich HL. Role of computing in patient care in two hospitals. *MD Comput* 1989;6:41–48.
9. Safran C, Sands DZ, Rind DM. Online medical records: a decade of experience. *Methods Inform Med* 1999;38:308–312.
10. Slack WV, Slack CW. Patient-computer dialogue. *N Engl J Med* 1972;286:1304–1309.
11. Fishbach RL, Sionelo-Bayog A, Needle A, Delbanco TL. The patient and practitioner as co-authors of the medical record. *Patient Couns Health Educ* 1980;2(1):1–5.
12. Mukamal KJ, Smetana GW, Delbanco T. Clinicians, educators, and investigators in

- general internal medicine: bridging the gaps. *J Gen Intern Med* 2002;17(7):565–571.
13. Clifford JC, Horvath J, eds. *Advancing professional nursing practice: innovations and Boston's Beth Israel Hospital*. New York: Springer, 1990.
14. Beatrice DF, Thomas CP, Biles B. Grant making with an impact: the Picker/Commonwealth Patient-Centered Care Program. *Health Affairs* 1998;17:236–244.
15. Kantz B, Wandel J, Fladger A, Folcarelli P, Burger S, Clifford JC. Developing patient and family education services: innovations for the changing healthcare environment. *J Nurs Admin* 1998;28:2,11–18.
16. Sands DZ, Halamka JD, Pellaton D. PatientSite: a Web-based clinical communication and health education tool. *Health Information Management Systems Society annual conference*, Chicago, 2001.
17. Halamka JD, Szolovits P, Rind D, Safran C. A WWW implementation of national recommendations for protecting electronic health information. *J Am Med Inform Assoc* 1997;4(6):458–464.
18. Masys DR, Baker DB. Patient-Centered Access to Secure Systems Online (PCASSO): 8a secure approach to clinical data access via the World Wide Web. *Proc AMIA Annual Fall Symposium* 1997;340–343.
19. <http://www.rsasecurity.com/products/securid/tokens.html>, 2003.
20. Slack WV, Bleich HL. The CCC system in two teaching hospitals: a progress report. *Int J Med Inform* 1999;54:183–196.
21. Slack WV. *Cybermedicine: how computing empowers doctors and patients for better health care* (revised and updated edition). San Francisco: Jossey-Bass, 2001.

Consumer Informatics

Applications and Strategies in Cyber Health Care

Nelson, R.; Ball, M.J. (Eds.)

2004, XX, 168 p., Hardcover

ISBN: 978-0-387-40414-1