White Paper ■

Consumer Informatics Supporting Patients as Co-Producers of Quality

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A b s t r a c t   The track entitled "Consumer Informatics Supporting Patients as Co-Producers of Quality" at the AMIA Spring 2000 Congress was devoted to examining the new field of consumer health informatics. This area is developing rapidly, as worldwide changes are occurring in the organization and delivery of health care and in the traditional roles of patient and provider. This paper describes the key themes of the track; implications of the growing area of consumer health informatics; and recommendations for informatics research, design, and policy. Key themes that emerged from the panels and discussions involved changes in roles of consumers and providers; supporting a patient–provider–information technology partnership; virtual, not physical, structure for health care and health care information delivery; and health care as an integrated part of one's life. Panelists and participants at the Congress developed recommendations for informatics research, design, and policy, with an overarching focus on how to support the patient–provider–information technology partnership to provide more patient-centered health care. They recommended that AMIA take an active leadership role in consumer health informatics. Specific recommendations were made concerning research, new patient record systems, provider support, information access and evaluation, and policy and regulation.

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Changes are occurring in health care professionals' and patients' roles, health care practice, and the organization of health care delivery.[1] As the use of information technologies in health care explodes and consumer involvement increases, medical and health informaticians face new challenges. More and more, people are using information and communication technology to obtain health information.[2,3] With an entire new field of consumer health informatics developing, informaticians have the opportunity to play an important role in supporting the new partnership between providers, consumers/patients,* and information technology.

The track entitled "Consumer Informatics Supporting Patients as Co-Producers of Quality" at the AMIA Spring 2000 Congress was devoted to examining these changes and their implications for medical and health informatics. The track concluded with a set of recommendations that grew out of a series of panels and discussions. This paper describes the key themes of the track; implications of the growing area of consumer health informatics; and recommendations for informatics research, design, and policy.

Process

The consumer informatics track featured three panels. Speakers were drawn from major sectors in health care—clinical practice, industry, government, and patients/consumers. The panelists examined key trends and major issues concerning consumers' control of their health. In the kick-off session, speakers (Brennan, Flory, Rippen, and Slack; see Acknowledgments) gave an overview of the primary topics that shape the field of consumer informatics. They discussed what they think are the important trends and issues, why these are important, and what they mean

* See footnote on p. 312.

for medical informatics; specifically, the nature of health information, patient participation and shared decision making, clinician responses, and Web technology.[4,5] This panel was followed by a session of audience discussion and questions.

The track then continued with two panels in which commentators responded to and expanded on the ideas presented in the opening session, raised additional important concerns, and provided provocative commentary. Each of these sessions was divided between panelists' remarks and audience participation. The first commentator panel reflected perspectives of developers of successful consumer health applications (Dowling, Friedman, and Houston). The second commentator panel comprised experts in patient empowerment and Web site design (Frydman), philosophy and bioethics (Goodman), and economics and regulation (Temin).

Next, more than 50 people participated in a discussion and breakout sessions. After the entire group identified key research themes, directions for future activities, and policy needs, participants met in smaller groups to address the main issues that were raised. These groups recommended activities and identified issues, which were presented at the plenary session that closed the entire Congress.

What follows is a report based on panelists' remarks, audience discussion, and the breakout sessions. Analyses, opinions, and recommendations reflect the overall sense of the track, rather than the views of the author or any single participant.

Themes

Several key themes emerged at the Congress:

- Changes in roles of consumers and providers

- Support for a patient–provider–information technology partnership

- Virtual, not physical, structure for health care and health care information delivery

- Health care as an integrated part of each person's life

These themes reflect trends that are intertwined, as suggested in the following discussion.

Consumer health information both fuels and is fueled by changes in the roles of patients and providers. Patients are becoming increasingly empowered, and they expect more personal attention. Health care is no longer "contained" in an office or building but includes activities at home, at work, in the gym, and at the food store as well. Moreover, as the institutional walls surrounding health care delivery are breaking down, health care is being delivered in virtual space, so that a person can obtain information, and even health care itself, from a variety of places that are distant from each other and from the person. These changes are leading to redefinitions of "health care," "patient," "provider," and "practice." The boundaries of the health care delivery system are permeable and in flux, as geography and physicality are becoming less relevant to health care and health encounters.

At the same time, cost pressures are increasing for providers, patients, and payers. Patients, as the largest unused resource in health care, represent a partial solution to these pressures while also being an avenue for improving health care services. As pressures to control health care costs increase, care is shifting closer to the home, and decision making is involving the patient more than it did in the recent past.

Computers can be used to empower and enlighten patients and help forge a new partnership between patients and providers. To accomplish this, patients must take an active role in their own health care.[6,7] In many cases, they already manage aspects of their health care. Diabetics administer their own insulin, families keep birth and death records, parents keep track of when immunizations are due, and many people engage in exercise, diet, and other self-help activities. They make such important decisions as when to see a practitioner and whom to see. The capacity for partnership is already evident among patients and providers, and it is likely that with appropriate and targeted consumer health informatics tools, this partnership can be actualized further.

Trends

As clinicians and patients negotiate their expectations of each other and coordinate their roles, they need parallel services that provide just-in-time information for making health-related decisions.

Several major trends are evident in what consumers want and how it is being provided. First, consumers want personalized relationships with their clinicians, more than with a hospital, so that they get information that addresses their individual concerns and conditions. Second, consumers also want interactive tools to manage their health and diseases. For example, in the CHESS project, patients can use a decision aide to determine the treatment choice most consistent with their personal values.[8] Some of these inter-

active tools are being provided by disease management companies and health plans. Similar techniques are being used for health promotion as well (see, for example, Houston et al.[9]).

A third development is the growth of wireless technology, making it possible for people to monitor their diseases in much the same way that physicians do. The Telephone-Linked Care system,[10] which has been used in this way to monitor patients with chronic diseases like hypertension, is one example.

Fourth, we are seeing the decline of megaportals that provide information on a wide range of topics, from health to entertainment, and the rise of vertical portals that integrate information around a single theme, such as the prevention and treatment of cancer. These are being developed by for-profit companies and by companies in partnership with academic medical centers. In short, people want the same services in health care that they now can get via the Internet from the financial services industry. They want, and benefit from, highly personalized, customized, targeted, tailored information and, ultimately, care delivery and case management.[11]

Until recently, many health care organizations were reluctant to invest in Web sites. No longer is health information controlled by health care professionals, and no longer is information technology developed solely by medical or health care informaticians. Health information Web sites are being developed by hospitals, e-health ventures, managed care plans, and pharmaceutical companies. However, lack of systematic development efforts, lack of an organizational culture that promotes the use of the Web and Internet services, and lack of clear business plans have resulted in poor interfaces and limited tools on Web sites developed by some health care organizations. Consumers and patients also are developing Web sites, listservs, newsgroups, and other means to communicate among themselves and form online communities.[12,13]

Acceptance of general-purpose tools for clinical use is also growing. Providers and patients are seeking new ways to enhance communication.[14] E-mail is being used by patients and clinicians to communicate with each other.[15–17] In addition, new special-purpose devices, such as in-home monitoring systems, and new uses of common devices, such as telephone data entry, are improving communication between patients and providers and thus improving health management.[18]

The explosion of sites and services is giving rise to public and governmental concern over the quality of information, privacy issues, legitimacy, and changes in practice. At the present time, self-regulation activities are vigilantly undertaken by some consumer Web sites, with the online community demanding sufficient information to judge credibility. In addition, a new industry and new government services are forming to provide clearinghouses for quality information.

Codes of ethics, too, are a growth area fueled, in part, by poor-quality information, businesses' and providers' fears that they will lose credibility, and the public health impact of the Internet. The eHealth Code of Ethics is one effort to lay a foundation for this accountability.[19] The Internet Healthcare Coalition and the eHealth Ethics Summit are developing this ethics code, a strategy to enforce it, and a means of educating providers and the public about it. The code is meant to be international, inclusive, and comprehensive, developed by an open and public process, and focused on ethics rather than law. With a goal "to ensure that all people worldwide can confidently, and without risk, realize the full benefits of the Internet to improve their health," the Ethics Summit Working Group adopted eight principles—candor, honesty, quality, informed consent, privacy, professionalism, responsible partnering, and accountability. In line with their goals, further information about these efforts appears on their Web site, at www.ihealthcoalition.org/ethics/ethics.html.

Other ethics efforts have also been undertaken, as described in the *Journal of the American Medical Association*.[20] Among them are the Health on the Net Code of Conduct (HONcode) for medical and health Web sites, established by the Health on the Net Foundation,[21] and the principles set forth in "Health Internet Ethics: Ethical Principles for Offering Internet Services to Consumers" (2000),[22] which have been adopted by Hi-Ethics (Health Internet Ethics), a coalition of sites that offer health services, products, and information to consumers in the United States.

Challenges and Implications

The search for new ways to enhance health-related communication and supplement the interpersonal relationship between clinicians and patients has important implications for medical and health informatics. For at least 40 years, informatics development has assumed the primacy of the patient–provider encounter, and applications development has focused on the needs of providers or health care institutions. Data models have been based on episodic patient encounters, and patient records have been organized

around them, rather than around the life course of the individual patient. These episode-based, provider-focused approaches leave patients confused, since they are expected to integrate their own care, services, and information while the delivery environment changes. Instead, patient-centered systems need to be organized around the person involved.[23]

Consequently, medical and health informaticians need to build informatics tools that support the patient as a partner in health care and focus on the consumer, not the provider or institution. A three-way partnership is developing between patients, providers, and information systems, with synergistic interrelationships among the three.

People seek health care information from numerous sources. Innovative computer technologies are needed to support the diversity of information that is sought. The technologies should be available in the places where information is sought, and they should support communication processes that a person may use to interact with the health care system to foster a healthy life. In line with what consumers want and need, information technology tools should provide a personalized information flow between patients and providers so that patients can take an active role in managing their own health care. Furthermore, information provided in a tailored strategy that links behavior to health consequences can potentially have a favorable impact on a person's health. These services should be available with other information services on the Web.

In the process of creating such tools, consumers, providers, and informaticians must pay attention to ethical and social issues so that together they shape the future as they would like it to be, in terms of both how technology is used and what kinds of regulations are put in place. Certification and self-regulation, instead of only government regulation, are needed to ensure information accuracy and to help users evaluate the credibility of information providers and information sources.

Codes of ethics, however, can themselves be controversial. When these codes are established by industry groups, some people question whether there may be ulterior motives. Codes also can be viewed as counter-productive, because they may provide a false sense that ethical issues have been sufficiently addressed. One possible way to resolve these concerns would be to have an unbiased organization, such as AMIA, oversee the development of codes, monitor the application of these codes, and take responsibility for disseminating and revising them. AMIA, for example, could review the literature and

work already done by ethicists in relevant areas. An unbiased organization also could investigate what the issues are, where people see potential trouble spots and pressure points, and possible solutions. It could help ensure that, once written and accepted, a code becomes a dynamic document conditioned by evidence and real experience and is frequently revised accordingly. Furthermore, an organization like AMIA could provide educational opportunities that such codes present.

Recommendations

AMIA has, so far, not been an active player in the consumer informatics arena. The panelists and Congress participants concurred that AMIA should become actively involved in consumer health informatics. They advanced the idea of expanding the provider-institution model of informatics to better address the needs and realities of contemporary patient-centered health care. To this end, panelists and conference participants proposed a number of recommendations.

The key focus of the recommendations was how to support the patient–provider–information technology partnership to provide more patient-centered health care. As part of this focus, the recommendations concerned five areas—research, new patient record systems, provider support, information access and evaluation, and policy and regulation. Enumerated below are key considerations in each of these areas.

Research

Definitions, Terminology, and Roles

As definitions and roles are changing, we need to reconsider the terminology and what messages different words convey. Some dimensions of this research area include:

■ Deciding whether we are addressing "patients," "consumers," or "clients," by considering what these terms imply, in what situations each is appropriate, and whether definitions shift with situations†

■ Determining how the roles of patients (or consumers? or clients?) and providers are changing,

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†This paper reflects the difficulties in choosing the appropriate term, which is why more than one of them is used in different parts of the paper. This variation was not intended to convey any particular message or definition. Appropriate use of each of these terms, and other possible ones, clearly needs more thought, and the implications require further research.

and what implications these changes have for informatics

- Defining "empowerment" by considering who is being empowered, what they are empowered to do, and for what purpose

Design Issues

Numerous research considerations arise in designing, implementing, and evaluating new information sources and services to empower patients. These applications may include programs providing information, decision support, patient-to-patient communication, and patient–provider communication. Research issues include:

- Determining what constitutes a "patient's view" of information

- Determining what patients and providers want

- Evaluating what the best practices in designing information delivery are

- Researching what are effective means for knowledge engineering, so that knowledge can be transferred to the Web

- Delivering targeted, personalized, just-in-time information

- Assessing what affective messages are carried by the technology, either explicitly or implicitly

- Identifying which values are, or should be, embedded in system and interface designs

Individual Responses and Reactions

As the use of information and communication technology in health care spreads, we need to be concerned with how different people and groups respond to the technologies. Research issues need to be addressed with respect to:

- Discovering how different people interact with and react to different technologies (e.g., telephones, Web services, e-mail), information, and access methods

- Identifying ethical concerns

Industry, government, and social commentators are pushing for codes of ethics, while the informatics community has primarily been reactive. We need to explore the need for and utility of proposed codes. While building on current efforts, research is needed also to develop a proper foundation for identifying ethical principles.

New Patient Record Systems

New record systems are needed to integrate care by use of informatics tools rather than through either the patient or the provider. A new model of care should be developed to transcend the brief patient–clinician encounter, and records should be about the entire process of care. Informaticians need to design new clinical record systems that would:

- Be longitudinal, organized around the person, in addition to institutions or providers, and relevant to individual patients in managing their own care

- Situate care in the context of a patient's life, and not only in the business of the institution, with records that extend across a lifetime and across institutions

- Allow pathways to and through information services across a number of institutions, including the kinds of records a patient keeps at home

- Link to knowledge resources that may be dynamic and frequently changing

- Integrate knowledge that patients and providers each need

- Integrate information and care across institutions, requiring a balance between information integrity and care needs

- Support epidemiologic, public health, and statistical analysis so that information could be provided back to clinicians

- Give attention to identity, security, privacy, and trust issues

Provider Support

Providers as well as patients need support. Conference participants suggested ways to protect providers and encourage them to use new consumer informatics technologies. To provide tools for provider support, we need to:

- Determine how providers can best teach patients to access, evaluate, and use the information that is available to them

- Create databases of information, such as disclaimers concerning information, and case and tort law pertaining to new information technology tools

Information Access and Evaluation

The changes in roles of both patients and providers create educational needs in each group. Both providers and patients need to learn to access and evaluate infor-

mation and assess its value, benefits, risks, and liabilities. Educational models are needed both for clinicians and informaticians, to be taught in multi-disciplinary programs that address the multiple relationships among clinical, technical, social, organizational, governmental, and ethical considerations. AMIA needs to take action in supporting educational activities and identifying new professional roles.

- Educational efforts should include addressing consumer health informatics issues through developing informatics curricula, scheduling conference sessions, supporting working group activities, and generating or assessing standards for vetting information and standards for ethical information provision, access, and use.

- New professional roles may be needed for those who teach about information quality and searching—for example, information triage nurses to review information a patient brings to a clinical encounter, and clinical librarians or educators to teach people how to get information.

Policy and Regulation

The growth of new information sources and services raises societal and governmental concerns. Groundwork needs to be laid to help ensure reimbursement arrangements that do not create disincentives for clinicians to use the new technologies; accessibility, including accessibility of language, literacy level, and technologic tools and media; a speedy and appropriate response in case of disaster; and self-regulation and control over the technology and information by providers and consumers.

Conclusions

Consumer informatics is an exciting development that is creating new challenges and opportunities in medical and health informatics. Choices must be made. How can we reap the benefits of these new developments in health care organization and technology while preserving the human side of health care? Do we want health care to be like automated banking and telephone menu systems? These changes provide exciting opportunities for considering ethical, legal, and political issues as well as for developing new information tools and services. AMIA needs to take an active leadership role in this area.

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- **Bonnie Kaplan, PhD,** President, Kaplan Associates; Yale Center for Medical Informatics, Yale University School of Medicine

Keynote Panel:

- **Patricia Flatley Brennan, RN, PhD,** Moehlman Bascom Professor, School of Nursing and College of Engineering, University of Wisconsin–Madison

- **Joyce Flory, PhD,** President, Communications for Business and Health, Chicago, Illinois

- **Helga E. Rippen, MD, PhD, MPH,** Chair, Internet Healthcare Coalition; Co-chair, eHealth Ethics Summit; IEEE-USA Medical Technology Policy Committee. Formerly, Director of Medical Informatics, Pfizer Health Solutions, Inc.

- **Warner V. Slack, MD,** Professor of Medicine and Psychiatry, Harvard Medical School; Co-Chief, Division of Clinical Computing, Beth Israel Deaconess Medical Center; Co-President, Center for Clinical Computing.

Commentator Panel–1:

- **Alan F. Dowling, PhD,** CEO, Global Health Technology Inc.; Adjunct Professor, Case Western Reserve University. Formerly, Partner, Global Health Care Consulting, Ernst & Young LLP

- **Thomas K. Houston, MD, MPH,** Assistant Professor of Medicine, Director of the Section on Medical Informatics, Division of General Internal Medicine, University of Alabama School of Medicine

- **Robert H Friedman, MD,** Associate Professor of Medicine and Public Health, Boston University; Chief, Medical Information Systems Unit, Boston Medical Center

Commentator Panel–2:

- **Kenneth W Goodman, PhD,** Director, Bioethics Program, University of Miami

- **Gilles Frydman,** Founder and President, ACOR (Association of Cancer Online Resources), and Member, Advisory Board, Cancer Trials Web Site, National Cancer Institute; Board, Internet Healthcare Coalition; Communications Opportunity Leadership Team, National Cancer Institute; Advisory Board, Oncology.com; Board, Colon Cancer Alliance

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References ■

1. Kaplan B, Brennan PF, Friedman CP, Peel V. Toward an informatics research agenda: key people and organizational issues. J Am Med Inform Assoc. 2001;8:235–41.

2. Internet users. 1999. Cyber Dialogue Web site. Available at: http://www.cyberdialogue.com/resource/data/ic/index.html#data. Accessed 11/00.

3. Miller TE, Reents S. The health care industry in transition: the online mandate to change. New York: Cyber Dialogue, 1998.

4. e-Health Ethics Summit Offers World International Code of Ethics for the Health Internet [press release]. Feb 18, 2000. Available at: http://www.ihealthcoalition.org/about/press.html. Accessed 11/00.

5. Slack WV. Cybermedicine: How computing empowers patients for better health care. Medinfo. 1998;9(pt 1):3–5.

6. Greenfield S, Kaplan SH, Ware JE. Expanding patient involvement in care: effects on patient outcomes. Ann Intern Med. 1985;102:520–8.

7. Greenfield S, Kaplan SH, Ware JE, Yano EM, Frank HJL. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. J Gen Intern Med. 1988;3:448–57.

8. Gustafson DH, Robinson TN, Ansley D, Adler L, Brennan PF. Consumers and evaluation of interactive health communication applications. The Science Panel on Interactive Communication and Health. Am J Prev Med. 1999;16(1):23–9.

9. Houston TK, Cooper LA, Vu HT, Kahn J, Toser J, Ford DE. Screening the public for depression through the Internet. Psychiatr Serv. 2001;52(3):362–7.

10. Friedman RH, Kazis LE, Jette A, et al. A telecommunications system for monitoring and counseling patients with hypertension: impact on medication adherence and blood pressure control. Am J Hypertens. 1996;9:285–92.

11. Kreuter MW, Strecher VJ, Glassman B. One size does not fit all: the case for tailoring print materials. Ann Behav Med. 1999;1(4):276–83.

12. Ferguson T. Health Online: How To Find Health Information, Support Groups, and Self-help Communities in Cyberspace. Reading, Mass.: Addison-Wesley, 1996.

13. Goldstein D, Flory J. The Online Guide to Healthcare Management and Medicine: The Best Online Sites, Resources and Services on Healthcare Management, Pharmacology. Burr Ridge, Ill.: Irwin Professional Publishers, 1996.

14. Slack WV. Patient-computer dialogue: a review. In: Bemmel J, McCray AT (eds). Yearbook of Medical Informatics 2000: Patient-centered Systems. Stuttgart, Germany: Schattauer/IMIA, 2000:71–8.

15. Kane B, Sands DZ. Guidelines for the clinical use of electronic mail with patients. The AMIA Internet Working Group, Task Force on Guidelines for the Use of Clinic-Patient Electronic Mail. J Am Med Inform Assoc. 1998;5(1):104–11.

16. Sands DZ, Safran C, Slack WV, Bleich HL. Use of electronic mail in a teaching hospital. Proc Annu Symp Comput Appl Med Care. 1993:306–10.

17. Sands DZ. Using e-mail in clinical care: a practical approach combining the best of high tech and high touch. The Informatics Review [online serial]. Mar 1, 2000. Available at: http://www.informatics-review.com/thoughts/pat-email.html.

18. Friedman RH, Stollerman JE, Mahoney DM, Rozenblyum L. The virtual visit: using telecommunications technology to take

care of patients. J Am Med Inform Assoc. 1997;4:413–25.

19. eHealth Ethics Initiative. eHealth Code of Ethics. May 18, 2000. Internet Healthcare Coalition Web site. Available at: http://www.ihealthcoalition.org/ethics/code0524.pdf. Accessed 11/00.

20. Winker MA, Flanagin A, Chi-Lum B, et al. Guidelines for medical and health information sites on the Internet: principles governing AMA web sites. JAMA. 2000;283(12):1600–6.

21. Health on the Net Foundation (HON) Web site. Available at: http://www.hon.ch/Honcode/. Accessed 11/00.

22. Ethical Principles for Offering Internet Services to Consumers. Hi-Ethics (Health Internet Ethics) Web site. 2000. Available at: http://www.hiethics.org/. Accessed 11/00.

23. Alemi F, Mosavel M, Stephens RC, Ghadiri A, Krishnaswamy J, Thakkar H. Electronic self-help and support groups. Med Care. 1996;34(10 suppl):OS32–44.

Further Reading ■

Demonstration and Evaluation of Consumer
Health Informatics Applications

Balas EA, Jaffrey F, Kuperman GJ, et al. Electronic communication with patients: evaluation of distance medicine technology. JAMA. 1997;278(2):152–9.

Brennan PF. Characterizing the use of health care services delivered via computer networks. J Am Med Inform Assoc. 1995;2(3):160–8.

Brennan PF. Health informatics and community health: support for patients as collaborators in care. Methods Inf Med. 1999;38(4–5):274–8.

Brennan PF, Kuang Y-S, Volrathongchai K. Patient-centered information systems. In: Bemmel J, McCray AT (eds). Yearbook of Medical Informatics 2000. Stuttgart, Germany: Schattauer/IMIA, 2000:79–86.

Brennan PF, Ripich S. Use of a home-care computer network by persons with AIDS. Int J Technol Assess Health Care. 1994;10(2):258–72.

Brennan PF. The future of clinical communication in an electronic environment. Hol Nurs Pract. 1996;11(1):97–104.

Brennan PF. Harnessing innovative technologies: What can you do with a shoe? Nurs Outlook. 1999;47(3):128–32.

De Vries H, Brug J. Computer-tailored interventions motivating people to adopt health promoting behaviours: introduction to a new approach. Patient Educ Couns. 1999;36(2):99–105.

Feenberg AL, Licht JM, Kane KP, Moran K, Smith RA. The online patient meeting. J Neurol Sci 1996;139(suppl):129–31.

Fisher WP Jr. A research program for accountable and patient-centered health outcome measures. J Outcome Meas. 1998;2(3):222–39.

Gustafson DH, Hawkins R, Boberg E, et al. Impact of a patient-centered, computer-based health information/support system. Am J Prev Med. 1999;16(1):1–9.

Houston TK, Ehrenberger H. The potential for consumer health informatics. Semin Oncol Nurs. 2001;17(1):41–7.

Jadad AR, Gagliardi A. Rating health information on the Internet: navigating to knowledge or to Babel? JAMA. 1998;25;279(8):611–4.

Lancaster T, Stead LF. Self-help interventions for smoking cessation. The Cochrane Library. Oxford, UK: Update Software Ltd, 1999.

Robinson TN, Patrick K, Eng TR, Gustafson D. An evidence-based approach to interactive health communication: a challenge to medicine in the information age. Science Panel on Interactive Communication and Health. JAMA. 1998;280(14):1264–9.

Widman LE, Tong D. Requests for medical advice from patients and families to health care providers who publish on the World

Wide Web. Arch Intern Med. 1997;157:209–12.

Winograd T, Bennett J, De Young L (eds). Bringing Design to Software. Reading, Mass.: Addison-Wesley, 1996.

Ethical and Regulatory Issues

Boyer C, Selby M, Scherrer JR, Appel RD. The health on the net code of conduct for medical and health websites. Comput Bio Med. 1998;28(5):603–10.

Kohles MK. Person-centered code of practice/code of ethics: configuring an ethical commitment to the care provider and care receiver. Semin Nurs Manag. 1998;4:205–13.

Perspectives on Involving Patients in Health Information Access

Brfez SM, Tailor M. Assessing literacy for patient teaching: perspectives of adults with low literacy skills. J Adv Nurs. 1997;5:1040–7.

Chaffee M. Health communications: nursing education for increased visibility and effectiveness. J Prof Nurs. 2000; 16(1):31–8.

Guidry JJ, Walker VD. Assessing cultural sensitivity in printed cancer materials. Cancer Pract. 1999;7(6):291–6.

Kaplan SH, Greenfield S, Ware JE. Assessing the effects of physician–patient interactions on the outcomes of chronic disease. Med Care. 1989;27(3 suppl):S110–27.

Kronenfeld JJ (ed). Patients, Consumers, Providers, and Caregivers. Greenwich, Conn.: JAI Press, 1995.

Martin ER, Lanier D. Networking consumer health information: bringing the patient into the medical information loop. Bull Med Libr Assoc. 1996;84(2):240–6.

Reis J, Wrestler F. Consumer attitudes towards computer-assisted self-care of the common cold. Patient Educ Couns. 1994;23(1):55–62.

Literature Reviews and Compendia

Brug J, Campbell M, van Assema P. The application and impact of computer-generated personalized nutrition education: a review of the literature. Patient Educ Couns. 1999;36(2):145–56.

Temin P. Taking Your Medicine: Drug Regulation in the United States. Cambridge, Mass.: Harvard University Press, 1980.