

# Preface

More than 70 million Americans have used the Internet to research health issues, and, according to a December 2002 survey from the Pew Research Center, 6 million go online each day to get health information. The Pew survey indicates that, with more than 100,000 active health information Web sites, two thirds to 80% of consumers feel they can filter the information to get what they want. A similar study conducted in 2001 by the U.S. Department of Commerce (DOC) indicates that 75% of U.S. households with annual incomes of at least \$50,000 a year have access to the Internet, while another DOC study, conducted in 2002, demonstrates that 34.9% of U.S. consumers seek information online about health services or medical practices. To substantiate further the consumer's passion with online health services, a survey conducted by Cyber Dialogue in May 2000, which focused on who consumers trust online, shows that consumers trust their own doctors first (62%), followed by national experts (61%), followed by online information posted by hospitals (58%). Other research reflects that as many as one third of all queries to major Internet search engines are health related, covering all aspects of healthcare delivery, disease management, medications, herbal therapies, and home treatment alternatives.

These statistics are indicative not only of the pervasiveness of the Internet in consumers' quests for healthcare information but also of their reliance on the accuracy of that information. These attitudes also reflect the characteristic of a dominant group of today's population—Baby Boomers and Generation Xers—who are health conscious, technologically savvy, and who do not readily accept the status quo. These trends are expected to continue and expand as the Baby Boomers age. At the same time, healthcare providers continue to harness the capabilities of the Internet, creating new opportunities and new paradigms for the delivery of healthcare information, and, most importantly, for the delivery of health care itself.

Consumer empowerment and active interaction between consumers and the Internet is a trend that was foreseen as early as a decade ago, in 1993, by Dr. Thomas Ferguson. A pioneering physician, author, and researcher, Ferguson has been studying and writing about the empowered medical con-

sumer since 1975, and about online health resources for consumers since 1987. In 1993, Ferguson and several other early pioneers who were developing information technology (IT) systems designed for use by healthcare consumers organized a conference sponsored by Healthwise Inc. and the National Wellness Association. The conference, *Consumer Health Informatics: Bringing the Patient Into the Loop*, took place on July 16-18, 1993, in Stevens Point, Wisconsin, and reflected the first appearance of the term *consumer health informatics* in both the conference brochure and the proceedings. Needless to say, the topic generated nationwide interest, and at the 1993 annual meeting of the American Medical Informatics Association (AMIA), Ferguson and Dr. Warner Slack presented a half-day tutorial, entitled, "Consumer Health Informatics: Bringing the Patient into the Loop," in which they discussed the advent of IT systems specifically designed for use by healthcare consumers. At the time, Ferguson proposed that a role change was in the offing in the physician-patient encounter. Whereas in the past the physician had taken on a role of authority and the patient one of compliance, Ferguson posited that in the future the physician's role would be more like that of "tech support," where the customer describes the problem to be fixed, articulates the desirable result, and reports when satisfaction has been achieved. In describing this scenario, Ferguson became the first to coin the term *consumer health informatics*, as reflected in the AMIA records. The first AMIA publication on consumer health informatics was the manual that Ferguson and Slack prepared for the 1993 AMIA tutorial. Since that time, other national associations and conferences, such as the Healthcare Information and Management Systems Society and the National Managed Health Care Congress, have sponsored education sessions focused on bringing patients, their families and friends, and consumers in general "into the loop" via information, technology, and virtual communities.

The result of these efforts has been a paradigm shift that now makes this book a necessity for both those *providing* and those *seeking* healthcare information on the Internet. As such, this book is of interest to healthcare administrators, IT professionals, and healthcare practitioners. It is also an invaluable tool in healthcare informatics training programs, for no development occurs today where informaticians are not concerned. Finally, it also speaks to consumers determined to seek empowerment within the healthcare system.

As expert healthcare informaticians, the editors of this volume have structured it to explore those technology-enabled applications that may very well become the cornerstones of our evolving healthcare systems. Woven through the volume is also an emphasis on the empowerment of all involved, whether they are healthcare professionals, laypersons, or consumer recipients of health care. Each chapter describes the role of computers, technology, and telecommunications (CTT) as enablers within a specific application focused on consumers' needs. These applications empower professionals in their efforts to serve those who are ill and those who are well. The applications are also ones

that empower consumers as they seek information, analyze their unique healthcare needs, and make decisions about their own health. By focusing on empowerment in the service of health for all, the book illustrates the issues raised by consumer informatics through actual examples. Whether addressing disease management, bioterrorism surveillance/detection, or traveler health, the contributors illustrate how CTT can strengthen the human element in health care.

More specifically, the book utilizes both applied use and pragmatic examples to address the information needs of patients and consumers in three distinct areas: collaborative healthware, research and development, and telemedicine and telehealth. An introduction to each section provides the context for the applications presented in the individual chapters and in addition highlights other issues and areas not covered in the volume. In the sections and actual applications described, the technology is presented as an enabler, and the authors, therefore, provide greater focus on business practices, consumers' acceptance, use of the technology, and policy issues.

Section I, for example, defines collaborative healthware and explains why this is the next compelling step for consumer health informatics. In collaborative health care, cooperation among stakeholders will allow health systems to do business in different ways. Four chapters show how this approach is currently being applied in diverse settings. Examples include the management and empowerment of vulnerable populations; a patient-centric Web-based system that allows secure messaging and allows patients to schedule appointments, order prescription refills, and interact with their own medical records; a Web-based information and support system for patient home recovery after surgery; and a statewide effort in the care of elderly patients that utilizes a virtual hospital and virtual nurse visits at home.

Section II addresses initiatives under development that include the use of CTT to support public health and biodefense and disaster management; to set standards of quality for information found on the Internet; and to provide secure access to computerized patient records.

Section III presents a panoramic view of the interactive use of telemedicine and the consumer in disease management, home telehealth, online communities, and computer-consumer interviewing. New educational paradigms, such as distance learning for medical, nursing, and online consumer communities, are also discussed.

The authors and editors recognize that we are only at the early stages of realizing the value that consumer health informatics can offer to consumers and the population at large. Broader understanding of consumers' expectations and broader dissemination of the technology will lead to second-level benefits that can include design and implementation of public health interventions, improving population health, and evaluating the use of these technologies. According to a 2002 Harris Survey, 90% of U.S. adults who use the Internet would like to be able to e-mail their physicians to ask whether or not a visit is

necessary (77%); schedule appointments (71%); refill prescriptions (71%); and receive the results of medical tests (70%). More than a third stated that they would be willing to pay out-of-pocket for the ability to communicate online with their physicians. More than half said they would be influenced to choose a doctor or a health plan that offers online patient services over one that does not. Many physicians have concluded that communicating with patients online offers as many benefits to providers as it does to patients. A recent Healtheon survey found that 33% of physicians have begun communicating with patients by e-mail, up from an estimated 1% to 2% only 2 years earlier.

Consumers are *demanding* that we capitalize on the use of CTT to service their healthcare needs. We challenge you, our readers, to join us in taking consumer health informatics to the next level. We hope you enjoy this book!

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Consumer Informatics

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