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Chapter 1

E-Health Research

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MOTIVATIONS FOR THE BOOK

The popularization of the Internet (so far, primarily in developed countries) and its opportunities and challenges have already significantly influenced society. In the health care field, access to online resources and environments is having a major and controversial impact on its stakeholders, users, providers, and institutions. The book presents an in-depth introduction to the field of Internet and health care, from both international and interdisciplinary perspectives. The interdisciplinary and critical perspective combines expertise from social sciences, medicine, policy, and systems analysis. It is the expression of a new generation of e-researchers and practitioners committed to excellence in investigating a new and still little-known phenomenon.

The idea for this book originated in 2002 at the third Association of Internet Researchers (http://www.aoir.org) conference in Maastricht, when Monica Murero and Susannah Fox co-founded the International Network of Excellence in E-Health Research (INEHR). The purpose of the INEHR is to research, study, teach, support, and create diverse and dynamic elements to the impact of the Internet on the health care field. It had become evident that the new field of Internet and health care had grown and matured since the time when people relied only on the words of their family doctor when dealing with a medical threat or deciding to simply keep themselves in good health. Further, much more research and projects have been developed since that time, especially internationally. A search on Amazon.com for books since 2000, using just the two keywords "Internet" and "health," returned 46 books. Some were not relevant, whereas almost all the rest were guides to online resources, manuals on developing health-related Web sites, guides about safe Internet searching, or books for medical specialists or administrators. The two exceptions are the edited books *The Internet and Health Communication: Expectations and Experiences* (Rice & Katz, 2001) and *E-Therapy: Case Studies, Guiding Principles, and the Clinical Potential of the Internet* (Hsiung, 2002).

AUDIENCE

The book is suitable for university educators and students in the social, public health, and medical disciplines, including Internet researchers. Public health and medicine workers will find the book helpful. It is also oriented to professionals in many disciplines who might appreciate an integrative theoretical, empirical, and critical analysis of the subject matter, including developers and providers of online health information. Health care policymakers will be interested in understanding the impact of the recent diffusion of the Internet provided in this book. Methods and data used in the chapters include personal interviews, focus groups, observations, regional and national surveys, online transcript analysis, online controlled experiments, secondary data analysis, case studies, systems analysis, policy analyses, and literature reviews.

RELATED SOURCES

There are several major medical informatics associations and journals, as well as many more associations, conferences, online communities, academic and continuing education organizations, and foundations that emphasize health care, health communication, and the Internet. Examples include:

- The American Medical Informatics Association (http://www.amia.org)
- The Association of Internet Researchers (http://www.aoir.org)
- The Health and Science Communications Association (http://www.hesca.org/index.asp)
- The Health on the Net Foundation (HON) (http://www.hon.ch/HONcode/HON_CCE_en.htm#5)

- The International Communication Association (http://www.icahdq.org)
- The International Ehealth Association (http://www.cdh.luth.se/cdh/ExternalLinks/ieha/view)
- The International Medical Informatics Association (http://www.amia.org)
- The International Network of Excellence in E-Health Research (http://www.air-e-health@listserv.aoir.org)
- The Medical Informatics Section (http://www.medinfo.mlanet.org) and the Consumer and Patient Health Information Section (http://www.caphis.mlanet.org) of the Medical Library Association
- The National Communication Association (http://www.icahdq.org)
- The National Communication Association (http://www.natcom.org)
- The Society for the Internet in Medicines (http://www.internet-in-medicine.org).

Several international conferences are organized every year, such as MedNet (http://www.mednet2004.com.ar./en/index.php), and hundreds host e-health related panels and roundtables. There are many journals that dedicate articles and special issues to health care, health communication, and the Internet, such as *Academic Emergency Medicine*; *American Journal of Medical Science*; *BMC Medical Informatics Decision Making*; *British Medical Journal*; *Bulletin of the World Health Organisation*; *Computer Methods and Programs in Biomedicine*; *Computers in Nursing*; *Health Care News*; *Health Management Technology*; *International Journal of Medical Informatics*; *InternetHe@lth: Journal of Research, Application, Communication & Ethics*; *Journal of Healthcare Information Management*; *Journal of Medical Internet Research*; *Journal of Online Behavior*; *Journal of Telemedicine & Telecare*; *Journal of the American Medical Association*; *Journal of the American Medical Information Association*; *Journal of the Medical Library Association*; *Social Science & Medicine*; *Student Health Technology and Informatics*; and *Telemedicine Journal and E Health*.

CONTENTS OF THE BOOK

We decided to focus on the relation between the Internet and health care to investigate a very specific but extraordinary innovation, rather than disperse our efforts in the broader field of telemedicine, although other ICTs are considered here in some contexts. The book simultaneously tries to build theoretical perspectives in light of empirical evidence and applications, and to foster integration among researchers, health care providers and health information seekers. The book also highlights some of the challenges that the Internet presents to the health care field, policymakers, providers and users, in different contexts.

Nonmedical individuals going online to find information and support is a rapidly growing phenomenon in developed countries. The international perspective of the book is crucial: although much of the early work has been done in North America, many exciting developments are happening around the world. In Europe, Asia, Australia, and South America, "online health seekers" are growing rapidly and studies on this new phenomenon are in increasing demand. Thus, we explicitly invited researchers and practitioners from a variety of countries (Canada, Germany, Indonesia, Italy, New Zealand, Peru, Singapore, Sweden, The Netherlands, and the United States). However, although an increasing number of medical and nonmedical public do access the Internet resources, more than one sixth of the world population live in extreme poverty and struggle for survival every day. The book invites policymakers to help remove barriers to the access in developing countries by clarifying problems and opportunities.

The book includes, in addition to Part I which is this introductory chapter, four parts with 17 chapters, subject and author indexes, as well as a chapter entitled "About the Contributors." The next four parts of the volume cover, in sequence: Part II reviews current trends and relevant theory; Part III explores health information seeking and evaluating at the individual level of analysis; Part IV discusses health information at the group or community level of analysis; and Part V implements health information systems at the regional and social level of analysis. Each part of the volume and its chapters are summarized in the following sections.

Part II: E-Health Trends and Theory

Part II provides comprehensive introductions to and reviews of trends in e-health, e-research and e-learning, e-commerce, and health and media use theory relevant to studying and implementing online health care.

Chapter 2: Laura Gurak and Brenda Hudson—"E-Health: Beyond Internet Searches." This chapter examines two key but currently underexamined applications in e-health: clinical service and health care professional education. These applications include electronic medical records and research networks, tele-homecare, and virtual clinics, to name a few. Privacy has significant implications across e-health applications. The chapter review illustrates the powerful ways in which digital technology can enhance human health, but also the problematic issues that are raised, including international and intercultural issues.

Chapter 3: Monica Murero—"E-Research and E-Learning: Could Online Virtual Environments Help Doctors Take Better Care of Patients?" This chapter investigates two contexts: (1) e-learning and e-research virtual environments designed for doctors. It questions two central issues: the validity of e-learning environments to educate and train medical students and practitioners online, by overcoming traditional learning boundaries of space, time and place, and (2) the validity of e-research environments to overcome classic constraints for the production, access and exchange of medical advances within the international scientific community. It also assesses the coverage by 93 medical associations' Web sites. The chapter investigates whether Internet-based learning and research environments have the potential to help doctors take better care of patients. It reflects on the opportunity of introducing attentive policies to help close the digital—and cultural—medical divide, in light of future scenarios that are expected to deeply impact medical research and revolutionize health care in the next few years.

Chapter 4: Pamela Whitten, Charles Steinfield, and Lorraine Buis—"The State of E-Commerce in Health: An Examination, Diagnosis, and Prognosis." This chapter assesses the state of e-health for purposes other than the delivery of health-related information. The examination of commercial e-health activity is directed by two major areas. The first part discusses the current utilization of commercial e-health, both in terms of business-to-consumer (B2C) and business-to-business (B2B) models. The second part presents several barriers and impediments to the growth of online health-related commercial activity and indicate how these barriers have changed over the last 5 years. Overall, a prediction made by Whitten et al. (2001), that "click and mortar" online health enterprises will become more common, is supported. There are many factors that complicate the success of commercial online health services and products. Despite these complicating factors, trends show that B2B commercial activity can be efficient for all involved and B2C commercial activity suggests that more and more Americans expect the presence of online commercial health service and product activity to grow.

Chapter 5: Mohan Dutta-Bergman—"Media Use Theory and Internet Use for Health Care." The use of the Internet for health care has grown dramatically in the last few years. Given the increasing use of the Internet by the health care consumer, it is especially important to examine the theoretical bases of Internet use for health care purposes. This chapter reviews key theories of media use and health behavior in order to provide a theoretical foundation for examining the motivations that drive the uses of the Internet for health care purposes. First, the chapter discusses four key theories of media use: uses and gratifications theory, selective processing theories, elaboration likelihood model, and the theory of channel complementarity. In discussing these, the chapter highlights the functional approach to Internet use for health care, positing the role of consumer motivation in the different uses of the Internet for health purposes and the subsequent information processing outcomes related to these different uses. The functional approach to Internet is further complemented by health behavior theories such as the stages of change model, the extended parallel process model, and the personality-driven health communication model that further articulate the role of audience motivation in health behaviors.

Part III: Searching, Discussing, and Evaluating Online Health Information

Part III considers individuals' use of the Internet to seek online health information, focusing on personal motivations and outcomes, implications for physician–patient interaction, applications in remote locations and nontraditional medical contexts, and quality of online health information.

Chapter 6: Evelyn Tang and Waipeng Lee—"Singapore Internet Users' Health Information Search: Motivation, Perception of Information Sources, and Self-Efficacy." This chapter analyzes and compares e-health seekers' and nonseekers' motivation, perception, and self-efficacy, using the focus group method. Results show that information sources can act as surveillants (to scan the environment), excavators (to acquire specifics), or verifiers (to validate information and treatments). The main reasons for information search are curiosity, personal health management, control, and provision of social support. Overall, participants believe in the Singapore press, are cautious about e-health, and show varying degree of trust toward interpersonal sources. E-health seekers are efficacious in discerning information quality and in handling information overload.

Chapter 7: Ulrika Josefsson—"Patients' Online Information-Seeking Behavior." Patients are increasingly searching the Internet for medical information to cope with illness and a changed life situation. However, few studies have addressed patients themselves and how they find their way through the vast amount of medical information online.

Therefore, with the objective to give voice to the patients, this chapter identifies and analyzes patterns in their online information-seeking behavior. Using a qualitative analysis of 18 in-depth interviews with Swedish patients, the chapter captures important components of the complex picture of patients' information seeking on the Internet. Informed by ideas from information science, the presentation of the empirical data is structured around features in Wilson's (1997) general model of information behavior. Three themes (accessing online information, social support, and information accuracy and applicability) derived from the empirical data serve as the basis for a discussion on the consequences associated with the search behaviors observed in the studies. Balancing factors (coping strategy, resource requirements, and online information-seeking assistance) complement the discussion in order to provide a nuanced picture of the outcomes of the participants' online information seeking.

Chapter 8: Ronald E. Rice and James E. Katz—"Internet Use in Physician Practice and Patient Interaction." The Internet can be part of a technological bridge that can help both patients and physicians better manage health care processes and information because more than half of Internet users in the United States seek health care information online. Although there has been good delineation of the types of activities for which health information seekers and physicians use the Internet, the interface of these two areas—how health information seekers and physicians bring the Internet-assembled information to bear on one another—is less clear. Thus, this chapter looks at these relationships in greater detail. The research review and analyses are organized by use of the Internet by physicians and by patients, and outcomes relevant to physicians and to patients.

Chapter 9: Sarah Stewart—"Delivering the Goods: Midwives' Use of the Internet." Midwives are people who provide maternity care for women and their families. In the New Zealand (NZ) context, a midwife is responsible for the provision of care to a woman from conception until 6 weeks after the baby is born. Midwifery care relies heavily on personal one-to-one communication and physically "being there." Some would argue that e-health is "dangerous nonsense" and there is no place for computers and the Internet in the midwifery practice environment; after all, being a midwife means "being with woman" not "being with computer." However, health consumers are increasingly accessing health information and resources via the Internet, which is bound to have implications with regards to midwifery practice and how midwives utilize the Internet. This chapter discusses the results of a web-based survey that questioned New Zealand midwives about their use of Internet resources. The study sought to find out what resources midwives used and wanted to be developed, and the barriers to use of the Internet. The study also aimed to discover how consumers' use of the Internet affected midwifery practice and how midwives felt about it.

Chapter 10: Joshua Seidman—"The Mysterious Maze of the World Wide Web: How Can We Guide Consumers to High-Quality Health Information on the Internet?" Most existing tools designed to help consumers find credible Internet health information focus almost exclusively on proxy measures of quality, such as the characteristics of the site sponsor and whether the site lists its sources. This analysis of 90 diabetes sites found that these proxy measures do little to explain the comprehensiveness of and accuracy of the information provided. The chapter lays out an alternative strategy for helping consumers find accurate and comprehensive Internet health information.

Part IV: Support Groups and Communities

Part IV analyzes how Internet health information users come together in online support and discussion communities; discusses some of the benefits, dangers, and concerns of this; and how such communities might be intentionally supported through social-science based systems analysis and design.

Chapter 11: Gerald Kral—"Online Communities for Mutual Help: Fears, Fiction, and Facts." The contents and possible effects of virtual self-help or mutual groups are controversial. Moreover, there is little study in German-speaking online environments for self-help. This chapter presents two empirical studies: one study involves an online forum for people suffering from eating disorders and the other, an online forum for people with suicidal thoughts. The study investigated (1) how virtual self-help groups work, and (2) the possible effects for participants. The results indicate that online groups have an important value for mutual emotional support of participants, and there is nearly no evidence for dangerous effects from participating in these online support groups. The two studies are compared and discussed in the light of previous literature.

Chapter 12: George Barnett and Jennie Hwang—"The Use of the Internet for Health Information and Social Support: A Content Analysis of Online Breast Cancer Discussion Groups." This study investigates the content of messages posted by participants of online breast cancer discussion groups. Prior research of online discussion groups primarily focused on the social support provided for breast cancer patients and their families. However, these individuals also tend to have substantial health information needs as they attempt to cope with the disease. This study uses semantic network analysis to evaluate the content of five online discussion groups. The findings suggest that information materials should be constructed to address two major issues: (1) medical treatment (oncology, radiation, mastectomy [surgery] and chemotherapy [the use of tamoxifen]), and (2) social support. These topics should be useful in the production of both print and electronic materials designed to inform individuals about breast cancer.

Chapter 13: Jan Marco Leimeister and Helmut Krcmar—"Designing and Implementing Virtual Patient Support Communities: A German Case Study." Virtual communities can, theoretically, be described as a solution for meeting ubiquitous information and interaction needs. Such needs occur in health care, when, for example, freshly diagnosed cancer patients develop very strong information and interaction needs. But how can such a platform for cancer patients be designed, implemented, and introduced practically? What specifications must a possible technical infrastructure meet? The COSMOS project addresses these topics. Besides these aspects, new technological possibilities like mobile services and mobile devices are influencing virtual communities. Subjects like ubiquitous community access, new possibilities of user identification, and location-related services are of special interest because they might allow real anytime–anyplace access to the community platform. Thus new, value-adding services to community members could be added. But only socially accepted, technically stable, and economically feasible solutions can ensure sustainable success of (mobile) virtual health care communities.

Part V: Practice and Infrastructure

The chapters in Part V provide detailed applications of Internet and related technologies for more regional and societal applications and interventions than individual online health information seeking, or online support communities. Thus issues of infrastructure, designed interventions, and socioeconomic and policy factors are relevant here.

Chapter 14: Kier Wallis and Ronald E. Rice—"Technology and Health Information Privacy: Consumers and the Adoption of Digital Medical Records Technology." New technologies offering improvements to consumers' daily lives are subject to scrutiny regarding the technologies' ability to maintain information security and privacy, important values among today's consumers. Medical information systems that combine digital technology with the highly personal and sensitive information contained in medical records, are increasingly examined as to their ability to achieve their stated medical function, while maintaining a level of privacy consistent with the government's medical privacy legislation. The Santa Barbara County Care Data Exchange (SBCCDE), a major regional health infrastructure project is in the process of implementing digital medical records technology in Santa Barbara County, California, and is subsequently subject to evaluation by its consumers, composed of the general public and medical community. In preparing for the diffusion of digital medical records technology, it is appropriate to investigate those consumer perceptions and concerns that might determine the success or failure of the new system. Therefore, this research investigates—through stakeholder interviews, focus groups, and a survey—consumer concerns, knowledge, and level of awareness regarding several facets of individual medical records technology and privacy.

Chapter 15: Suzanne Brunsting and Bas van den Putte—"Web-Based Computer-Tailored Feedback on Alcohol Use: Motivating Excessive Drinkers to Consider Their Behavior." This chapter analyzes the effectiveness of computer-tailored interventions targeting excessive alcohol users who are not inclined to seek treatment. The aim of these interventions is to make these people aware of the excessiveness of their drinking and the possible negative consequences. The term *computer tailoring* is explained and illustrated with examples of recently developed interventions, followed by a discussion of the theory underlying computer tailoring. The chapter also contains a description of a small-scale study on the effects of a Dutch computer-tailored intervention. Results of this study are used to raise and discuss several issues, resulting in implications for future research on computer tailoring.

Chapter 16: Lorna Heaton—"Telehealth in Indigenous Communities in the Far North: Challenges for Continued Development." The chapter begins with a description of the situation in Nunavut, Canada and the challenges of delivering health care across a large number of remote, isolated communities. It draws a portrait of medical practices in this context and describes how telehealth is changing these practices and the relationships between the various parts of the system. The chapter then points to several elements that may be generalizable from this specific case to discuss lessons learned and challenges for continued development. Since telehealth is still in the early stages in Nunavut, this part of the chapter is speculative. Finally, the chapter discusses policy issues and

potentials for development, such as the use of the Internet. Insights from telehealth programs in other Northern contexts are introduced in support of the argument.

Chapter 17: Indrajit Banerjee and Cecilia Hsi-Shi Leong—"ICTs in the War Against HIV/AIDS in Asia." In most developing countries in Asia studied in this chapter, universal access is not a certainty due to factors such as the digital divide, economic considerations, or literacy levels. Nevertheless, the Internet does provide an alternative avenue (and in that sense, increases the options) for access to information. More specifically, there are AIDS-related Web sites that are targeted at specific audiences, such as women, adolescents, families affected by AIDS and ethnic minorities. This chapter discusses how ICTs, in particular the Internet, have been used in the battle against HIV/AIDS across South Asia (India, Pakistan, Sri Lanka), South East Asia (Indonesia, Malaysia, Thailand, and Vietnam) and East Asia (China and Mongolia). The chapter reviews the prevalence of HIV/AIDS in these Asian countries, how widespread it has become and also how the Internet is being used by various HIV/AIDS interest groups for support. It also discusses the use of the Internet for HIV/AIDS monitoring, research, and education as well as how networking effects of the Internet have generated synergies between health care providers, researchers, policymakers, and PLWHAs. The chapter reviews what all these mean in terms of implications and challenges for Asia.

Chapter 18: Walter Curioso—"New Technologies and Public Health in Developing Countries: The Cell PREVEN Project." Computers and personal digital assistants (PDAs) are limited in developing countries because of their expense and requirement for additional equipment, such as relatively complex network connections. Cell phones, which are ubiquitous and cheaper than most computers and PDAs, offer a simple solution to a paper-based system. This chapter describes an application of telehealth using cell phones and the Internet to collect, transmit, and monitor data in real-time from female sex workers (FSW) who are part of a 20-city randomized trial in Peru to reduce sexually transmitted diseases (STDs). Early detection and treatment of STDs represents one major strategy for preventing transmission of STDs, including infection with HIV. New technologies and information systems can help public health in terms of prevention, surveillance, and management of public health data. The chapter discusses some barriers, factors, and limitations in collecting data electronically in a developing country. Despite some limitations, cell phones have a valuable role in bridging the digital divide and providing solutions in public health. The chapter also addresses the importance of developing an appropriate technology and collaborating with information technology partners, and provides some lessons learned that can be generalized to other developing and developed countries.

TOPICS ACROSS THE CHAPTERS

In addition to the specific focus, reviews, and results of each chapter, the chapters overall represent a wide array of research, theory, and practice issues relating to Internet and health care. A brief analysis of the 17 chapters reveals 11 general categories of topics: theories and constructs, levels of analysis, methodological approaches, advantages, disadvantages, facilitators, barriers, policy issues, lessons learned, trends, and developments. The following sections provide brief comments about each general category, and a listing of the specific forms of the category across the chapters.

Theories and Constructs

Because of the inherent interdisciplinarity of technology-mediated health care, applicable theories come from a wide variety of domains, such as persuasion, health communication, organizational behavior, psychology, sociology, management, consumer behavior, privacy studies, public health, communication, information systems, and information science (see Table 1.1). Of particular note is the application of theories of human information seeking, community sustainability, system design, and integrated health communication.

Levels of Analysis

In addition to the usual short list of possible levels of analysis—individual, group, organization, community, social, national, cross-cultural—the chapters discuss or imply several other ways to conceptualized levels of analysis (see Table 1.2). One is the important role of professions, which are diverse within health care institutions and cross institutional boundaries. Specific professions have different needs, criteria, and concerns. For example, nurses are concerned both about patient safety and privacy, but also the extent to which technology may interfere with providing personal attention. Another interesting way to conceptualize levels of analysis is that an individual user may have multiple online identities and accounts, whereas multiple users may share the same account. So levels of identity and access become intertwined. A third perspective would consider the intermediary technology users between pa-

TABLE 1.1
Topics Across the Book: Theories and Constructs

- accessibility
- activating mechanisms that generate information seeking
- behavior modeling
- brief/minimal health interventions
- channel complementarity/functional equivalents
- collective knowledge
- community platform engineering process
- comprehensive model of health information seeking
- consumer motivations
- contingencies of practice
- coping strategies (including coping with web-based health information overload)
- critical mass
- diffusion of innovations
- digital divide
- dual (cognitive) processing (elaboration likelihood model, heuristic systematic model)
- economies of scale
- evidence-based practice
- extended parallel process model
- gap between physicians and patients on evaluation and use of Internet health information
- gatekeeping
- health belief model
- health orientation
- health care professionals' practices
- hyperpersonal interaction
- idiocentrism
- information asymmetries
- information behavior model
- information literacy
- information need context
- informed consent
- innovation clusters
- lurking
- media access and control
- media use as functional to different audience segments in different contexts
- message involvement and salience
- need for privacy
- online empathy
- online health business models (click and mortar, online–offline alliance, commission)
- online niche markets
- online self-help groups
- online/virtual community
- prevention versus treatment motivations for health information seeking
- professional identities
- proxy measures of health information quality
- quality of online health information
- quality-of-care measurement
- reinvention
- role model perception

(Continued)

TABLE 1.1
(Continued)

- scalable health community system platforms
- search modes (passive attention, passive search, active search, ongoing search)
- security
- selective processing (exposure, interpretation, retention, recall)
- self-efficacy
- self-monitoring
- self-perceived health risks (such as alcohol consumption)
- sensation seeking
- social influence
- stepwise and emotional model of information seeking
- strength of weak ties
- subjective norms
- supply chain management
- technological fit
- technology acceptance model
- third-party Web site accreditation
- transaction cost theory
- transtheoretical model
- transtheoretical stage transitions
- trust
- ubiquitous health information needs
- uncertainty reduction during threat to quality of life
- uses and gratifications
- web fluency

TABLE 1.2
Topics Across the Book: Levels of Analysis

- accounts may be shared by multiple users
- business-to-businesses
- communicating and collaborating with other professionals in specialty area
- markets and industry, such as B2B and B2C e-commerce
- group/social identity
- individual user may have multiple online identities and accounts
- individuals-to-businesses
- information seekers versus information sources
- intermediary technology users between patients and health care providers
- managers of online support/self-help groups as opposed to individual users of the support group
- online health seekers with same diagnosis
- online support groups allow anywhere from an intimate group of friends to an unknowably large and changing number of people with shared interests to discuss illnesses and treatments, provide behavioral examples and emotional support, and create awareness about otherwise rare conditions
- shift among relationships such as general group support to dyadic chat or offline meeting
- team or sequence of health care providers jointly offering diagnosis and treatment
- transaction chains involving intermediaries

tients and health care providers, and managers or moderators of group discussion lists.

Methodological Approaches

The research reported here uses a wide array of methodologies (see Table 1.3). Indeed, studying the complex interactions among stakeholders, users and their family and friends, technology, information, law and regulation, economics, medicine, and social and cultural values requires multiple methodological approaches. Of course, the nature of the Internet provides opportunities for new types and venues for methods and analysis, such as online surveys, Web site features and content analysis, and

TABLE 1.3
Topics Across the Book: Methodological Approaches

- archival/document analysis
- case studies of health organizations
- case study
- content analysis of Web sites
- cost-effectiveness analysis
- developing reliable health Web site evaluation measures
- ethnography
- focus groups
- information systems design requirements and analysis for online health communities
- key stakeholder personal interviews
- literature review
- multidimensional scaling to visually portray relationships among words in online or focus group transcripts
- narrative interviews
- ongoing formative evaluation
- online pre–post field/quasi-experiment
- qualitative interpretation of online discussion group transcripts
- randomized treatment/control field experiment
- recruiting online respondents through snowball sampling
- semantic analysis of online transcripts and focus group discussions
- semi-structured personal or video-based interviews
- survey and focus group pre-testing
- system prototyping
- thematic analysis of focus group discussions
- usage session monitoring forms
- user needs analysis for system design
- using general and medical search engines
- using search engine results as a sampling procedure
- web-based and telephone surveys
- Web site content analysis
- Web site feature analysis

usage monitoring for interface design. The textual and storage nature of online discussions also provide opportunities for analyzing large and over-time transcripts.

Advantages

Potential advantages of Internet and other mediated health information, communication, and service capabilities are familiar and frequently noted, such as reduced cost, increased access, and the ability to overcome time and space (see Table 1.4). Some of these are the flip side of disadvantages, such as benefits to those who are shy or uncertain who are able to "lurk" and learn without posting on discussion groups. Others are more sense-making, whereby discussing one's own experiences and reading others helps develop one's own sense of identity as well as commonality. And others are based on the possibilities for real-time interaction and tailoring of content, and the linking of different media to and from Web sites.

Disadvantages

Additionally, the flip side of some advantages are potential disadvantages, such as anonymous postings fostering deception and lack of accountability (see Table 1.5). Certainly, central concerns involve the fact that as anyone can publish any information on the web (depending on the country of the author), there is little guarantee of the quality, accuracy, and authoritativeness of the information or identity of the author. Another ongoing debate is whether the powerful focus of discussion groups also fosters narrowness and social fragmentation.

Facilitators

Continued diffusion, application, and benefits of Internet health care and communication requires ongoing, and additional, facilitators (see Table 1.6). Obvious ones include broadband infrastructure and funding, but less obvious ones involve patient involvement in their own health care decisions, interconnectivity across systems and media, appropriate regulation and legislation, and support from medical associations and health agencies.

Barriers

As with advantages and disadvantages, the flip side of some facilitators are barriers (see Table 1.7). The fundamental problem of digital divides is that usage of Internet health care information requires technological,

TABLE 1.4
Internet Health Information: Advantages

- access to alternative medicine products and information
- access to emotional and social support from a broad range of others who share same experience and concerns
- adds value
- allows some who are not comfortable posting messages to "lurk"
- anonymity for posting personal health information and problems
- connects those who are geographically or professionally isolated from colleagues
- emotional support
- faster diffusion of medical research
- finding/communicating with/evaluating health providers
- foster development of online communities
- foster development of social and professional health care networks beyond patients/individuals and beyond system users
- general versus tailored health information
- greater access to diverse sources of health information
- greater provision at lower cost in residential and rural homes
- help patients make sense of their medical experience (such as cancer)
- improve patient empowerment and self-care
- improve processes
- improve self-presentation in discussing medical conditions with others
- increase access
- increased interaction and discussions with physicians (due to e-mail, and bringing in printouts of Internet health information)
- Internet information improves doctor–patient communication and has variety of other positive patient outcomes
- less risk in online self-disclosure
- message tailoring and stages of readiness assessed through interactive choices
- more personalized and customized information and interactions
- not just receive, but also provide social support or the more broad experience of generalized reciprocity and sharing
- online health insurance applications and registration
- physicians interacting with better-informed patients
- provide clinical support to nonphysicians
- provide support for peer counseling
- reduce health care costs
- reduced errors (such as in prescriptions, confusing different patients' medical records)
- reduced social status cues
- reduces face-to-face hierarchical barriers
- reducing errors and delays in obtaining personal medical records
- scheduling flexibility in taking online medical education courses
- switch from telephone calls to online information provision
- therapeutic value of self-disclosure
- wide access to at-risk groups through online health campaigns and interactive interventions

TABLE 1.5
Internet Health Information: Disadvantages

- access to unregulated drugs
- access to unverified alternative medicines and information
- allows some to "lurk" and "free ride"
- benefits require technical expertise and skills and medical knowledge
- bypassing checks for drug interactions
- challenges to physicians by patients with Internet information
- commercial biases in health and prescription sites
- complex and difficult to understand online medical information
- e-mail interaction with patients generates considerable demands on staff and raises liability issues
- inaccuracy of online health information
- inappropriate access by third parties
- may require additional procedures and effort to use a new system
- missing or misleading Web site links
- narrow and self-reinforcing information and interactions
- poor quality information
- pressure on physicians to prescribe Internet-advertised medicines
- reinforcing eating disorders or suicide tendencies
- self-diagnosis and prescribing
- unreliable networks or storage

TABLE 1.6
Internet Health Information: Facilitators

- broadband infrastructure
- collaboratives/cooperatives
- cooperation and coordination among service and infrastructure providers
- government promotion of access and infrastructure and e-health
- HIPAA standards
- interconnectivity across systems and channels
- mobile/wireless devices and interconnections
- more use of general Internet activities
- patients want to be involved in their medical decisions
- physician recommendations of health sites
- positive perceptions of innovation attributes
- reimbursement for online time and services
- support by national medical associations

TABLE 1.7
Internet Health Information: Barriers

- access and knowledge
- accountability and responsibility
- computer fears
- computer/ICT skills
- contention for system usage between administrators and health care providers
- cultural divides concerning technology use and social norms toward health behaviors
- differences in data conceptualization by physicians (narratives) and administrators (structured data entry)
- differences in procedures for reimbursement and health coverage across economic sectors and national boundaries
- difficulties in assessing online knowledge acquisition
- digital divide
- high costs of technology overwhelm low cost of access and communication
- HIPAA regulations
- individuals' perceptions of current medical information rights
- insufficient bandwidth
- insufficient control or awareness of third party access to personal medical records
- insufficient health staff
- joint involvement by local service providers/physicians/patients
- jurisdictional conflicts or disagreements
- lack of basic infrastructure
- lack of insurance reimbursement codes for online treatment
- lack of interconnection
- lack of standard evaluation criteria
- lack of support for sustainability of online interventions and health projects
- large gap between those with Internet access and those with many kinds of chronic health problems (such as HIV/AIDS)
- limited vision by government and health care agencies as to potential applications
- majority of health sites in English language
- national and cultural norms and policies
- online privacy concerns
- physician resistance/hesitancy
- poor management of ICT personnel and projects
- standard codes for practices and protocols
- state licensing laws
- sustainability (costs, updating, link stability)
- time required to learn new systems
- usability

educational, and economic resources and knowledge. Some aspects may challenge cultural norms and practices. Contention over limited resources and conceptualizations of system purposes by different organizational or political stakeholders can prevent users from benefiting. The same regulations that facilitate and protect the use of health information can also create obstacles, confusion, and complexity. Lack of sufficient and trained health care staff is often a more fundamental barrier. Concerns about online privacy and health information quality, resistance by some health professionals to technology mediation of health care, and lack of ongoing support for online projects and interventions are significant barriers.

TABLE 1.8
Policy Issues

- codes of ethics
- cross-state and cross-border drug prescription economics and regulation
- enforcement of online pharmacies
- health insurance portability and accountability act (HIPAA)
- health Web site licensure
- HIPAA
- identity theft
- interstate commerce conditions and criteria
- national/regional/international e-health policies
- privacy (collection, accessibility, security, anonymity, verification)
- telecommunications policy reform in developing countries
- telecommunications tariffs

Policy Issues

Policies—concerning everything from standards for interconnection and health information coding, to privacy, and telecommunications pricing structures—affect the governance and potentiality of all aspects of Internet health care, information, and communication (see Table 1.8). Specific medical associations may establish codes of ethics that health sites have to meet in order to be certified, while national e-health policies direct where funding and system development is targeted. Ineffective or contradictory policies can create both industry and user uncertainty and frustration, and misdirect scarce resources.

Lessons Learned

The traditional focus of many research studies on Internet and health care/communication of course is on factors influencing usage and outcomes, and many of the chapters here provide rich and comprehensive coverage of both the prior research and the reported research. Beyond that familiar sense of lessons learned, the chapters also provide more practical, institutional, and implementation insights (see Table 1.9). For example, assumptions about what users believe about their medical rights, or how search engines actually work, have significant implications for publicity about, and provision of, online health care. Fostering communication among users and stakeholders is as, or more, important, than providing accurate and understandable health information. Long-term planning, realistic expectations, adapting technology to local and cultural contexts, and understanding of how professionals' practice in-

TABLE 1.9
Lessons Learned

- advantages and disadvantages from same kind of use (such as active searching for online health information)
- allow personal recommendations and buddy lists among users
- allow ratings of health sites and content by users
- consumers not well informed (such as about medical rights, implications of privacy statements)
- content analyses of discussion groups sites can help understand users' concerns and interests and guide development of public health messages
- content analysis of discussion groups can lead to better system design and moderator activities
- emphasis on peer-to-peer advice and support than on discussion group moderators
- expectations about and attitudes toward use of a health information technology can influence actual use and outcomes
- few users understand how search engines work
- health care providers (such as midwives) may change/improve their practice due to online professional discussion lists
- health information sources as surveillants/excavators/verifiers
- health institutions and government sites more trusted for credible information
- implement with local partners
- implementation of new health information technologies can change and challenge traditional professional and administrative practice and roles
- information overload a problem but health seekers manage?
- Internet as information source and as communication medium
- Internet health interventions must fit local and cultural conditions and contexts
- lower tech solutions that better match users' contexts and professionals' practices more successful
- manage realistic expectations
- move from information retrieval and transmission to communication and interaction
- need for multiple forms of user involvement in health site design
- need long-term planning
- need to integrate expert judgment with technology
- online discussions may help alleviate some conditions such as suicidal thoughts or eating disorders, but do not seem to motivate users to obtain therapy or treatment
- online health seekers have different general health information source usage patterns
- patients' bringing Internet information to their doctor's appointments affected various outcomes for physicians and patients depending on how the physicians assessed the reliability of the information and their own attitudes toward general popular access to health information
- site map and orientation guides necessary for Web site designs
- social support and interpersonal utility needs
- structural indicators of Web site quality and accreditation seals may not be highly related to accuracy and quality of its medical content
- tendency toward using broad search engine searches instead of specific terms and topic-specific health sites
- understand required human resources
- understand users' needs and perspectives
- use iterative requirements specification in health community design
- use of some media may trigger use of Internet for more information

(Continued)

TABLE 1.9
(Continued)

- use online health information to compare and follow-up interpersonal (include physician) information
- users perceive shortcomings and complexity and credibility problems of Internet, but use it for health information anyway
- users rate online health information quality much higher than do physicians
- visualization of system prototypes helpful for users to understand and comment on design possibilities
- widespread use of Internet by physicians, but much less so for interaction with patients

teracts with new health technologies, are all important lessons learned from some of the studies reported here. Also important is the appreciation that users' beliefs and behaviors may be contradictory (such as about health information accuracy and privacy beliefs compared to evaluations of online searches), and may differ considerably from those of health professionals (such as between physicians and patients).

Trends

The chapters identify and discuss a wide range of general trends in the social, institutional, and professional contexts of Internet health care (see Table 1.10). Many of these are fundamental concerns about health information and communication, whereas some are quite recent entrants to the agenda. Some, for example, represent surprising uses, such as posting or video-streaming online surgeries and births, continuous monitoring of individual health status outside of a medical institution, and physician or hospital web portals. Others are more enduring issues, such as certifying the quality of health information, telehealth, and online publication of medical research.

Developments

There are ongoing developments in technologies and features, and new medical information and practice (see Table 1.11). Many of these are new systems or applications, such as collecting health information locally, transmitting it through text messaging on mobile phones into a web-based database, and tailoring this information for specific groups of users. Online diagnosis tools, miniaturization, voice-response applications, embedded wireless sensors, and high-speed broadband wireless networking are all providing researchers, designers and users new possibilities, as well as new challenges, obstacles, and questions.

TABLE 1.10
Trends

- accuracy and privacy certifications and criteria
- broadcasting baby births through the Internet
- business-related applications
- developing national medical databases such as providing online birth registries
- electronic patient records (digital medical records)
- electronic prescribing services
- electronic publication of medical research
- e-mail between health providers and patients
- health group discussion threads
- hospital and health resource portals
- image-management systems
- increased emphasis on health problems and disparities
- increased system security
- increasing business-to-consumer and business-to-business Internet transactions
- increasing online intermediaries
- massive increase in health care sector investments and expenses
- moderated health discussion sites
- online medical education (physicians, students, patient)
- online medical textbooks and journals
- online test results
- personalized and customized online portals and medical training
- physician referral of patients to health Web sites (including more formally as "information prescriptions")
- physicians turning to the Internet to keep up to date with current research
- point-of-care testing
- real-time and asynchronous monitoring and reporting individual health status as well as disease outbreaks and diffusion
- remote diagnosis
- rise of online transaction processing services
- technology-enhanced clinical applications
- telehealth in remote areas
- traditional print and broadcast media providing links to online health sites
- virtual clinics

CONCLUSION

Clearly the chapters in *The Internet and Health Care: Theory, Research, and Practice* represent a rich and diverse set of contributors, research and usage settings, insights, topics, and theoretical and methodological approaches. These chapters of course represent only a small portion of prior and current research in these areas, and also represent the early stages of a significant and rapidly growing domain of theory, research, and practice. We encourage you to pursue these and related topics in Internet and health care and communication, and to collaborate and communicate

TABLE 1.11
Developments

- context- or location-sensitive services
- disabled patients using embedded sensors to interact with their environment
- electronic learning environments
- electronic research environments
- evaluating e-health behavioral and management interventions
- high-speed broadband wireless Internet
- integration of various treatment and response media (such as online assessment generating advice to contact a telephone hot line or send an e-mail)
- interactive voice-response applications
- miniaturization
- mobile telephone-based or PDS-based health information and communication services
- nanomedicine
- online databases of rare pathologies and cases
- online diagnosis tools
- online health monitoring and personal health management
- online or mobile health monitoring or reminder systems
- online virtual specimen slides
- physically embedded monitoring sensors
- portable digital personal medical records
- regional health information organizations
- use of Internet for medical research networks
- using wireless devices as data entry interface for Internet-accessible databases, digital cameras to capture and transmit medical images
- virtual reality anatomy demonstrations and medical training
- visualization of internal bodily processes
- web-based store-and-forward health information applications (such as for X-rays)

with the current authors and the many others doing work on these topics. Helping to improve the health care and condition of people around the world, through the implementation, application and understanding of the Internet and related information and communication technologies, is one of the most important contributions we, as theorists, researchers, and practitioners, can make. We hope this book aids this effort.

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