2001

# The **e**Health Landscape

A TERRAIN MAP OF EMERGING INFORMATION AND COMMUNICATION TECHNOLOGIES IN HEALTH AND HEALTH CARE



Preparation of this publication was supported by a contract from The Robert Wood Johnson Foundation<sup>o</sup> to Thomas R. Eng of EvaluMetrix LLC.

# The eHealth Landscape

# A TERRAIN MAP OF EMERGING INFORMATION AND COMMUNICATION TECHNOLOGIES IN HEALTH AND HEALTH CARE

ForewordEvaluMetrix, LLC, who is responsible for the views, content, and citations referenced in this publication.PrefaceThis publication is available online at The Robert Wood Johnson Foundation Web site at www.rwjf.org.AcknowledgementsHard copies are also available by writing to:Executive SummaryHard copies are also available by writing to:IntroductionCommunications Office The Robert Wood Johnson Foundation P.O. Box 2316Current Status of the eHealth SectorP.O. Box 2316Perspectives of Major eHealth StakeholdersFeedback:Overview of Major eHealth IssuesFeedback:Overview of eHealth referent Internet-Related Trends and Their ImplicationsSuggested citation: Function Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8	Table of Contents	Preparation of this publication was supported by a contract from The Robert Wood Johnson Foundation to Thomas R. Eng ( <u>www.evalumetrix.com/leadership.htm</u> ) of
AcknowledgementsThis publication is available online at The Robert Wood Johnson Foundation Web site at www.rwjf.org.Executive SummaryHard copies are also available by writing to:IntroductionCommunications Office The Robert Wood Johnson FoundationCurrent Status of the eHealth SectorP.O. Box 2316 Route 1 and College Road East Princeton, New Jersey 08543-2316Perspectives of Major eHealth StakeholdersFeedback: E-mail: publications@rwjf.orgOverview of Major eHealth IssuesFeedback: E-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions to releatthcopyright@2001 by The Robert Wood Johnson Foundation SIBN 0-942054-14-8	Foreword	
AcknowledgementsWeb site at www.rwjf.org.Executive SummaryHard copies are also available by writing to:IntroductionCommunications Office The Robert Wood Johnson FoundationCurrent Status of the eHealth SectorP.O. Box 2316 Route 1 and College Road East Princeton, New Jersey 08543-2316Perspectives of Major eHealth StakeholdersE-mail: publications@rwjf.orgOverview of Major eHealth IssuesFeedback: E-mail us your feedback/comments: ehealthcomments@rwjf.orgNew of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8	Preface	
Executive SummaryHard copies are also available by writing to:IntroductionCommunications Office The Robert Wood Johnson FoundationCurrent Status ofP.O. Box 2316the eHealth SectorRoute 1 and College Road East Princeton, New Jersey 08543-2316Perspectives of Major eHealth StakeholdersE-mail: publications@rwjf.orgHealth StakeholdersFeedback:Overview of Major eHealth IssuesE-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Internet-Related Trends and Their Implicationscopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8		This publication is available online at The Robert Wood Johnson Foundation
IntroductionCommunications Office The Robert Wood Johnson FoundationCurrent Status of the eHealth SectorP.O. Box 2316 Route 1 and College Road East Princeton, New Jersey 08543-2316Perspectives of Major eHealth StakeholdersE-mail: publications@rwjf.orgOverview of Major eHealth IssuesFeedback: E-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8	Acknowledgements	Web site at <u>www.rwjf.org</u> .
Current Status of the eHealth SectorThe Robert Wood Johnson FoundationCurrent Status of the eHealth SectorP.O. Box 2316Perspectives of Major eHealth StakeholdersE-mail: publications@rwjf.orgVerview of Major eHealth IssuesFeedback:Overview of Major eHealth IssuesE-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson FoundationInternet-Related Trends and Their Implicationscopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8	Executive Summary	Hard copies are also available by writing to:
Current Status of the eHealth SectorP.O. Box 2316 Route 1 and College Road East Princeton, New Jersey 08543-2316 E-mail: publications@rwjf.orgPerspectives of Major eHealth StakeholdersFeedback: Feedback: E-mail us your feedback/comments: ehealthcomments@rwjf.orgOverview of Major eHealth IssuesFeedback: E-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8	Introduction	Communications Office
the eHealth SectorRoute 1 and College Road East Princeton, New Jersey 08543-2316Perspectives of Major eHealth StakeholdersE-mail: publications@rwjf.orgFeedback:Feedback:Overview of Major eHealth IssuesE-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8		
Perspectives of Major eHealth StakeholdersPrinceton, New Jersey 08543-2316 E-mail: publications@rwjf.orgOverview of Major eHealth IssuesFeedback: E-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8		
Perspectives of Major eHealth StakeholdersE-mail: publications@rwjf.orgOverview of Major eHealth IssuesFeedback: E-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8	the eHealth Sector	
eHealth StakeholdersFeedback:Overview of Major eHealth IssuesFeedback:Cutionary View of eHealthE-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Internet-Related Trends and Their Implicationscopyright©2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8		
Overview of Major eHealth IssuesFeedback:2 Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Internet-Related Trends and Their Implicationscopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8		E-mail: <u>publications@rwjf.org</u>
Overview of Major eHealth IssuesE-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Internet-Related Trends and Their Implicationscopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8	eHealth Stakeholders	
eHealth IssuesE-mail us your feedback/comments: ehealthcomments@rwjf.orgA Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Internet-Related Trends and Their Implicationscopyright@2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8		Feedback:
A Cautionary View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright©2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8		
View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright©2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8	eHealth Issues	E-mail us your feedback/comments: ehealthcomments@rwjf.org
View of eHealthSuggested citation: Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright©2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8		
Internet-Related Trends and Their ImplicationsEng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright©2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8		Suggested citation:
Internet-Related Trends and Their ImplicationsThe Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright©2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8		Eng, T.R. The eHealth Landscape: A Terrain Map of Emerging Information and
and Their ImplicationsThe Robert Wood Johnson Foundation, 2001.Key Questions for eHealthcopyright©2001 by The Robert Wood Johnson Foundation ISBN 0-942054-14-8	Internet Deleted Trends	
Key Questionscopyright©2001 by The Robert Wood Johnson Foundationfor eHealthISBN 0-942054-14-8		The Robert Wood Johnson Foundation, 2001.
Key QuestionsISBN 0-942054-14-8for eHealth	and men implications	
for eHealth	Key Questions	
		ISBN 0-942054-14-8
Reterences	References	

**Appendices** 



#### **Foreword**

**Preface** 

**Acknowledgements** 

#### **Executive Summary**

#### **Introduction**

<u>What is eHealth?</u> <u>What is the Role of eHealth in Health and Health Care?</u> Who is Using the Internet and Online Health Resources?

## **Current Status of the eHealth Sector**

Commercial Sector Activities eHealth Business Models How Healthy are eHealth Companies? Public Sector and Nonprofit Initiatives

#### Perspectives of Major eHealth Stakeholders

Consumers Application Developers Clinicians Policymakers Health Care Organizations Public Health Professionals Employers and Purchasers

# Overview of Major eHealth Issues

Quality Privacy, Confidentiality, and Security

Access and the Digital Divide Content and Application Development Research and Evaluation Data Standards Development Integration of eHealth Segments

A Cautionary View of eHealth

Fraudulent Activities and Poor Quality Resources Violations of Privacy and Confidentiality Unintended Errors Potential Misuse Social Isolation Widening the Socioeconomic Divide

# **Internet-Related Trends and Their Implications for Future eHealth Tools**

Internet Trends Communications Infrastructure Trends and Technologies Application Development Trends Biotechnology and Nanotechnology Trends

Key Questions for eHealth

**References** 

# **Appendices**

APPENDIX 1 - eHealth-related information resources. APPENDIX 2 - Comparative summary of most popular eHealth sites. APPENDIX 3 - Foundations with explicit interest in information and communication technology issues. APPENDIX 4 - Venture capital funds with a specific interest in eHealth-related investments. APPENDIX 5 - Non-profit organizations with major eHealth-related activities.



Foreword

#### **Preface**

**Acknowledgements** 

#### **Executive Summary**

**Introduction** 

# Current Status of the eHealth Sector

#### Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

#### Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

The pen, the printing press, the telephone, radio, and television— these are some of the pivotal technologies in history that have permanently redefined how we communicate with each other. In the last decade, the computer and the Internet have joined the ranks of these defining technologies.

Many observers believe that emerging information and communication technologies have great potential to address long-standing issues in health and health care, including quality, access, and cost. However, whereas many sectors of our economy, such as commerce and finance, have embraced and integrated such technologies into their operations, similar movement in the health sector has been relatively slow.

The Robert Wood Johnson Foundation® commissioned this overview of the eHealth sector to help provide a framework for engaging some of the important issues in this still embryonic but multidimensional field. It is our hope that it will facilitate further public discussions about the appropriate role of eHealth technologies in health and health care.

The ultimate impact of emerging information and communication technologies on how we achieve and maintain health and well being is unclear, but the Internet and its successors will certainly continue to alter our daily lives. Without doubt, in the years to come, society will be inspired, challenged, and surprised by the evolving opportunities— and some of the threats— embedded in Internet-facilitated technologies. It is vital that our institutions devoted to improving health and health care attend fully to these possibilities.

We welcome public dialogue about the issues raised by this report and encourage any thoughts you might have about issues of importance to the evolution of eHealth technologies, and, in particular, about ways you feel philanthropy might enhance their quality and availability.

#### J. Michael McGinnis, MD

Senior Vice President & Director, Health Group The Robert Wood Johnson Foundation



Foreword

**Preface** 

**Acknowledgements** 

**Executive Summary** 

#### Introduction

Current Status of the eHealth Sector

Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

This report provides a general overview of the status of eHealth in the United States. The purpose of this document is to summarize the major players, issues, and emerging trends and technologies in the eHealth arena so that stakeholders can make informed decisions in this area. Because of the enormous scope of the eHealth field and the desire to produce a reasonably compact document, this report provides a general discussion of major eHealth-related issues and does not attempt to capture all aspects of eHealth in detail. Although almost all aspects of eHealth are described, this document emphasizes those aspects of eHealth that may be most amenable to philanthropic and other noncommercial interventions.

The intended primary audience for this document is the reader who may have some familiarity with the Internet and eHealth, but may not have been actively involved in eHealth activities.<sup>1</sup> The most current sources of information were used in producing this work, but some portions of this document may become quickly outdated because of the dynamic nature of the Internet and information technology.

<sup>1</sup> Readers who are not familiar with Internet-related terms may wish to consult with any of the various online technology glossaries available (e.g., <u>help.tucows.com/eng/glossary.html#I</u>, <u>www.webopedia.com</u>).



Foreword

**Preface** 

#### Acknowledgements

**Executive Summary** 

**Introduction** 

Current Status of the eHealth Sector

Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

J. Michael McGinnis originally conceived this project. Members of the internal eHealth Special Working Group who provided project direction included: Carol Chang, John Fiorillo, Hinda Greenberg, Susan Hassmiller, Jean Lim, Joe Marx, Marianne Meyer, Robin Mockenhaupt (Co-Chair), Kristine Nasto, Tracy Orleans, Constance Pechura, Michael Rothman, Lois Shevlin, Sara Thier, Vicki Weisfeld, Anne Weiss, Judy Whang (Co-Chair), and Ennise Williams.

In addition, the following external advisors to this project provided valuable guidance and suggestions: William R. Braithwaite and Mary Jo Deering, U.S. Department of Health and Human Services; Deb Cablao, Intel Corporation; Steve DeNelsky, Sapphire Capital Partners; Tim Kieschnick, Kaiser Permanente; Bernard Lo, University of California, San Francisco; John R. Lumpkin, Illinois Department of Public Health; Kevin Patrick, Healthcentral.com and San Diego State University; Ted Shortliffe, Columbia University; Elliot Stone, Massachusetts Health Data Consortium; and Vic Strecher, Health Media, Inc. and University of Michigan Comprehensive Cancer Center.

Specific companies, organizations, or Web sites are mentioned in this document for the purposes of illustrating concepts and to provide examples of relevant resources. Their appearance does not imply endorsement, support, or disapproval of these entities by the author or by The Robert Wood Johnson Foundation.

# EXECUTIVE SUMMARY

#### Table of Contents

#### **Foreword**

**Preface** 

#### **Acknowledgements**

#### **Executive Summary**

#### Introduction

Current Status of the eHealth Sector

#### Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

#### A Cautionary View of eHealth

# Internet-Related Trends and Their Implications

Key Questions for eHealth

#### **References**

#### **Appendices**

We now have access to the largest volume of health information in history. People can seek support and advice from potentially millions of online peers and professionals worldwide at any time of day. Using the Internet, they can assess their health risks, fill a prescription, manage a chronic condition, decide on treatment regimens, and consult a health care provider without leaving their home. Emerging information and communication technologies promise to usher in a wealth of innovative solutions for seemingly intractable problems in health and health care, including quality, access, and cost.

Against this backdrop of unprecedented technological innovation, many aspects of the health and health care systems are in need of serious attention. These systems are ripe with inefficiencies, inequities, and errors. The United States spends more on health care than any other country, yet more than 44 million Americans do not have health insurance. In addition, between 44,000 and 98,000 people may die every year as a result of medical errors, and variations in medical practice may result in uneven patient outcomes. Increasingly, people perceive that they are ceding control of their health care decisions to institutions that have placed financial priorities above individual health needs. Although Americans have recently made inroads in some behavior-linked conditions, such as tobacco use and teen pregnancy, other health problems, such as physical inactivity and obesity, are at epidemic levels.

eHealth is the use of emerging information and communication technology, especially the Internet, to improve or enable health and health care. This term bridges both the clinical and nonclinical sectors and includes both individual and population health-oriented tools.

This overview of the eHealth sector addresses the following questions: What is the emerging field of eHealth? Who are the major players in this dynamic arena? What are the major eHealth issues? And, what are the emerging trends and technologies on the immediate horizon that will shape future eHealth tools?

# **Current Status of the eHealth Sector**

In January 2001, approximately 168 million (60 percent) of the total U.S. population had access to the Internet at home or work, and as many as 86 percent of adult Internet users accessed it to research information on health care or specific diseases. The number of health-related Web sites available is unknown, but it is widely believed that the more than 19,000 health sites indexed on Yahoo! as of May 2001 represent only a small fraction of the universe of eHealth sites. Although populations that have been traditionally underserved are less likely to have Internet access, the profile of Internet users is shifting from one comprised initially of largely white, educated, young men to a much more diverse group of users.

Compared to other industry sectors, such as finance and commerce, the adoption and integration of information technology in the health sector is unfolding much more slowly. As with most other Internet-related sectors, the eHealth field is being driven primarily by for-profit eHealth companies. At present, many of the most recognized eHealth companies are consumer-oriented portals that seek to be "onestop shops" for health information and health-related products. The most common focus of larger eHealth companies seems to be on providing tools, solutions, products, or services that support some aspect of clinical care or eCommerce, including administrative transactions, clinical information systems, telemedicine and telehealth, and sales of health-related products. With the exception of providing consumers with health information, few companies are focused on population-oriented eHealth tools partly because of perceptions about the viability and scope of this market segment.

Business models employed by eHealth entities include advertising, sponsorship, merchant, transaction fee, licensing, fee for service, clinical services, data and infomediary, and subscription models. In practice, many companies rely on a combination of revenue streams. Many commercial eHealth companies face an uncertain future as eHealth business models are still evolving. In addition, the long-term outlook for publicly traded eHealth companies is unclear, but the recent Internet stock market correction suggests that fewer eHealth companies will be going public in the next few years, and that venture capital will be more difficult to obtain.

As with other Internet-related sectors, the status of the eHealth arena is extremely fluid and characterized by rapid developments in the commercial and noncommercial sectors. During the last few years, traditional ("bricks and mortar") health corporations, which were initially slow to embrace the Internet, have become increasingly active in Internet-related ventures. As with many other sectors, such as retailing, traditional large health-related corporations, including pharmaceutical and health care companies, will increasingly enter the eHealth arena and compete or partner with or purchase smaller Internet-centric companies in the next several years.

During the last several years, federal, state, and local health agencies have been steadily increasing the variety of online health resources. Many federal agencies, particularly agencies under the U.S. Department of Health and Human Services, and nonprofit organizations sponsor eHealth-related initiatives. However, there is no federal eHealth coordinating agency or government-wide strategic plan for eHealth, nor is there a comprehensive inventory of federally sponsored eHealthrelated programs, except for a review of federal telemedicine programs. The two major federal agencies with regulatory authority over eHealth matters are the Federal Trade Commission (FTC) and the Food and Drug Administration (FDA).

Although most nonprofit health organizations were initially slow in using the Internet to further their charitable missions, many large organizations now have substantial eHealth activities and several have developed content and tools that compete with those sponsored by commercial sites. It is possible that nonprofit and public sector eHealth entities will gain market share going forward, and many nonprofit organizations, especially professional societies and universities, are continuing to develop formal partnerships with commercial companies. Nongovernmental organizations have also been playing an important role in eHealth issues, such as research and policy analysis, quality oversight, standards development, and information dissemination.

Return to Top

# Perspectives of Major eHealth Stakeholders

Major stakeholders with respect to eHealth development and use include consumers, application developers, clinicians, policymakers, health care organizations, public health professionals, employers, and purchasers. Understanding the various motivations and perspectives of these stakeholders is helpful in designing and implementing successful eHealth initiatives.

Consumers— who may be healthy individuals, patients, caregivers, or health professionals— are considered by many observers to be the ultimate drivers in the eHealth arena because they will ultimately decide which eHealth sites and tools will succeed or fail. The consumers' ability to drive many segments of the eHealth sector, however, will be constrained so long as the traditional decision-makers in health care spending (e.g., employers, payors, health plans) determine underlying financial incentives and the distribution of the health care dollar.

Developers of eHealth resources are an extremely heterogeneous group with

differing skills and resources. In the commercial sector, the need to be ahead of the competition and financial pressures to be profitable quickly may result in released products that are not fully bug-free or have not been completely tested and evaluated. Another common dilemma for developers is finding the balance between investment in marketing and product evaluation. For many developers, the competition to obtain capital (i.e., investment funding, grants, contracts) to support development efforts may discourage meaningful collaboration with other developers, potentially resulting in inefficiencies and duplication.

Clinicians, traditionally slow adopters of information technology, have gravitated dramatically to the Internet within the last few years. Although most physicians and other clinicians now use the Internet, a much smaller fraction has actually integrated the Internet into their practice. Clinicians are not routinely applying eHealth tools in the clinical setting, probably because the Internet does not yet save them substantial amounts of time or money, and may only marginally help them provide better care. Other barriers to the adoption of eHealth tools include legal and liability issues, lack of reimbursement, and the lack of applications that can be efficiently integrated into a clinician's workflow.

Both public and private policymakers, through legislation and regulatory initiatives and through purchasing, investments, and implementation decisions, respectively, determine the context in which eHealth applications are developed and deployed. In developing legislation and regulations, public policymakers balance the uncertainties associated with voluntary industry standards and self-regulation with more direct, but often unpopular, legislative and regulatory options. Government agencies have a major role in eHealth policy given their mandate to promulgate regulations governing related areas, such as data security, consumer protection and fraud, and approval and sale of prescription drugs and medical devices. In the private sector, health care executives and large employers essentially set eHealth policy within their organizations by virtue of their purchasing and implementation decisions.

Large health care organizations, such as health plans, hospital systems, and provider groups, have been longstanding users of clinical and administrative information systems. As a result, many of these institutions have sizable capital investments in legacy systems and may be somewhat reluctant to transition to Internet-based solutions. In addition, in the current context of narrow profit margins, many health care organizations are unable or reluctant to commit substantial resources for new information technology investment. Another impediment to the adoption of eHealth tools stems from the independent operating and competitive nature of many health care organizations.

Most public health institutions have been very slow in adopting and integrating information technology into their workflow because of inadequate training, lack of public health-oriented eHealth tools, and cost considerations. Online applications

that support public health functions are limited.

There are essentially two major drivers that influence employer policies and decisions about implementing eHealth tools: the containment of health care costs, which often accounts for a substantial proportion of corporate expenses; and enhancing employee health and satisfaction, which may lead to greater productivity, less absenteeism, reduced staff turnover, and reduced workers' compensation claims. Typically, purchasers seek higher quality and lower costs, and many consider the Internet to be an important vehicle to achieve their goals by facilitating transactions with health plans and other vendors.

#### Return to Top

#### **Overview of Major eHealth Issues**

#### Quality

As in the "offline" health care industry, quality assurance and improvement are major issues for the eHealth sector. Consequences of poor quality eHealth applications include inappropriate treatment or delays in seeking appropriate health care, damage to the patient-provider relationship, and violations of privacy and confidentiality. Proposed approaches to ensuring quality of eHealth resources include accreditation, certification, rating systems, public disclosure of key information about a site or product, and posting of seals and logos indicating compliance with a set of quality standards. A number of organizations have proposed competing standards and guidelines for eHealth sites, and further consensus building or unification of approaches may reduce confusion among the public. Regardless of which approaches to voluntary quality assurance and improvement are adopted, they will need to be evaluated for effectiveness in promoting quality or changing developers' and consumers' behavior. Because current quality assurance strategies were developed for relatively static health interventions, further efforts are needed to explore new models that address the dynamic nature of eHealth technologies.

#### Privacy, Confidentiality, and Security

In the last few years, several widely publicized breaches of network security and global viruses have elevated the issue of online data and computer security to the center of the public eye. Although the overwhelming majority of reported security breeches do not directly involve health-related data, they foster the perception that online data of any kind are susceptible to security threats. Americans fear that personal health data will be used to limit insurance coverage or to limit job

opportunities, and some of their fears about online privacy seem to be well founded. A recent analysis of the privacy policies and practices of 21 popular eHealth sites found that most did not meet minimum fair information practices, such as providing adequate notice and giving users control over their information. Until the public is confident that health information will not be shared or sold without their consent, and that databases are secure, many types of eHealth tools, such as electronic health records, will not be widely adopted.

Under the final rules of the Health Insurance Portability and Accountability Act (HIPAA), health plans, health care clearinghouses, and health care providers who conduct certain financial and administrative transactions electronically are required to disclose how they use, store, and share health information; ensure patient access to their medical records; and obtain patient consent before releasing patient information. The extent to which the HIPAA regulations will affect eHealth companies will depend on the nature of their operations. However, because the regulations are focused on health care providers, health plans, and health care clearinghouses, it will likely only cover eHealth companies that are directly involved in those sectors, and not eHealth entities that collect personal health information in other contexts.

#### Access and the Digital Divide

The term "digital divide" is most often used to refer to the gap in computer and Internet access between population groups segmented by income, educational level, race/ethnicity, age, disability, or other parameters. For example, in August 2000, households with incomes of \$75,000 or higher were more than six times as likely to have Internet access than families with incomes less than \$15,000. The contribution of various socioeconomic factors to the digital divide is controversial, but recent data suggests that the digital divide may be closing in some aspects. For example, although lower-income families account for a small proportion of all Web users, they represent the fastest growing segment of recent users and computer purchasers. Current efforts addressing the digital divide have largely focused on providing access to PCs, the Internet, and hardware and software training. Infrastructure access, however, is only one dimension of the digital divide, of which technology, health literacy, and appropriate content are also key elements. Despite current data showing that lower socioeconomic groups are increasingly gaining Internet access, it is likely that the digital divide will persist albeit with an evolving focus as new technologies become available. For example, as enhanced multimedia services and capability become integrated into Internet-based tools, broadband access may become as important for accessing future health care and other services as narrowband access is today for obtaining health information.

#### **Content and Application Development**

A variety of disparate individuals and entities are involved in eHealth development,

and, as a result, development efforts are typically uncoordinated and essentially independent— even within the public sector. Not surprisingly, there is considerable overlap and gaps in eHealth content. Current market forces are driving rapid eHealth development in some areas, such as clinical care support, health care transactions, and business-to-business commerce. Most eHealth sites and tools, however, do not offer population health-related functions, such as population-based registries and community health tools, perhaps reflecting the perception that implementing such functionality may not translate into substantial revenue. Although new business models that support development for small markets are evolving, market demand and investors are unlikely to spur development efforts in certain neglected areas. Therefore, it is likely that targeted efforts will be needed to address the gaps in eHealth development.

Many developers have limited expertise or experience in technical or topic-specific areas that are critical for product development and evaluation. Increased information exchange and collaboration among developers, and between developers and other stakeholders (e.g., developers and users, designers and evaluators) may result in more efficient uses of special expertise and development resources and the improvement of the quality and effectiveness of resulting applications. The challenge is to foster collaborative eHealth development in the context of market competition and the desire to safeguard proprietary approaches.

#### **Research and Evaluation**

eHealth interventions have been shown to enhance social support and cognitive functioning; enhance learning efficiency; improve clinical decision-making and practice; reduce health services utilization; and lower health care costs among certain study groups. Most assessments of eHealth interventions, however, have been limited to small groups that may not be representative of the parent population, have not been randomized control trials, had limited follow-up periods, or only assessed proprietary interventions that may or may not be replicable. eHealth developers do not routinely conduct evaluations, especially post-market assessment for effectiveness. And when commercial companies and other private sector organizations do conduct evaluations, the results are often not publicly available.

#### Data Standards Development

Many observers believe that a vision of convergent— or at least interoperable clinical, laboratory, and public health information systems appropriately linked to personal health information, will provide unprecedented opportunities for improving individual and population health services and knowledge. However, most current data systems are proprietary legacy systems running on various operating systems and platforms, and were conceived by dozens of different vendors. To enable universal data exchange capability, translating software is often required and data exchange standards will need to be developed.

#### Integration of eHealth Segments

The lack of integration and communication among the fields of health care, public health, and personal health also carry over into the online world. There is a need to integrate the various features and functions of eHealth tools, including health information and support, transaction processing, electronic health records, clinical and public health information systems, compliance and disease management programs, and behavior change and health promotion. In addition to potentially improving operational efficiencies in delivering health care and public health services, such integration promises to augment the ability of professionals to provide a seamless continuum of care. Although the Internet offers an unprecedented opportunity to integrate various health-related sectors, many longstanding political, economic, structural, and competitive barriers to collaboration and integration must still be overcome. And, with regard to information systems sponsored by public and private organizations, the lack of common data definitions and structure standards may make integration efforts unrewarding even if the political will for integration exists.

Return to Top

# A Cautionary View of eHealth

Although the promise of applying emerging information and communication technologies to improve health and health care is substantial, it is critical that enthusiasm for this prospect be tempered with an understanding of what technology can and cannot do. In addition, some observers contend that the Internet has been over-promoted as the solution for the inefficiencies, redundancies, and quality deficiencies in the U.S. health care system. Major potential risks associated with the widespread use and adoption of eHealth tools include fraudulent online activities and poor quality resources, violations of privacy and confidentiality, unintended errors from inadequately tested or complex tools, potential misuse of applications, increasing social isolation from online activities, and widening of the socioeconomic divide.

Return to Top

# Internet-Related Trends and Their Implications for Future eHealth Tools

Several Internet-related and other trends and technologies will have a substantial influence on the design, content, functionality, dissemination, and use of future eHealth tools. Anticipating the likely trends and technologies related to the Internet, communications infrastructure, application development, and biotechnology will help in identifying potential opportunities for proactive investment and policy development to enhance future eHealth tools and technology.

#### **Internet Trends**

The commercialization of eHealth will continue and perhaps become even more pervasive, but noncommercial entities will likely have a role in the future eHealth market. As the Internet becomes truly global, increasing numbers of eHealth resources will be developed overseas and for global audiences. Thus, issues such as communication barriers, cross-cultural factors, and international quality assurance mechanisms will be increasingly important. As current and subsequent generations of Internet users become increasingly immersed in technology, they will likely demand immediate and constant access to information and support, and will rely heavily on online resources to inform health and other decisions. One important emerging technology is the peer-to-peer network, which allows individual computers to function as both a server and a client without any central administrator. This technology may enhance certain health activities (e.g., research, information searching), increase the availability of both credible and unsubstantiated information, and potentially threaten the Web portal model.

# Communications Infrastructure Trends and Technologies

The emergence of broadband Internet service and access makes it likely that future eHealth applications will increasingly provide multimedia content, including full motion video. When traffic congestion issues on the current Internet are resolved and end-to-end quality of service is available, clinical eHealth services, such as realtime medical consultations, will be in high demand.

The current number of people worldwide with wireless Internet access is relatively small, but is expected to grow from 6 million in 2000 to 484 million by 2005. The advent of wireless Internet access is predicted to spur the growth of a new class of mobile eHealth applications for both providers and consumers. The trend toward non-PC-centric access (e.g., Personal Digital Assistants and other hand-held communication devices, Web-enabled phones, interactive TV, Web and email terminals, Internet gaming consoles) will encourage eHealth developers to cater to wider audience segments and spur development for a variety of access devices and formats.

#### **Application Development Trends**

Personalization and tailoring, with reference to interactive media, is the practice of dynamically altering content according to the profile, preferences, or usage patterns of an individual user. As personalization and tailoring become more common as components of eHealth sites and tools, increased online collection and use of potentially sensitive personal health information will raise privacy and data security issues.

Extensible Markup Language (XML), which was developed to address the shortcomings of Hypertext Markup Language (HTML), can be used to describe the meaning of content regardless of its display format. This will enable the development of innovative eHealth tools that are considerably more powerful and user-friendly than what we currently have. In addition, the growing use of Application Service Providers (ASPs) may enhance the availability of specialized eHealth tools, but may also result in privacy and data security considerations.

#### **Biotechnology and Nanotechnology Trends**

The decoding of the human genome and its subsequent biomedical advances will likely have as dramatic an impact on health and health care as the Internet will— if not more so. As the complexity and volume of genetic knowledge grow, both providers and consumers will become increasingly reliant on information technology to assist them in storing and interpreting the results of genetic testing and evaluating treatment options. As a result, new eHealth tools to support both clinician and consumer decision-making in genetics will be in great demand. In addition, nanotechnologies, such as cellular or sub-cellular sensors or computers, will generate novel methods and tools for collecting, storing, and analyzing Internetaccessible health data.

Return to Top

#### Key Questions for eHealth

Any of the previously described emerging technologies and trends is singularly powerful. Their convergence could shift basic paradigms in health and health care. Potential examples of such converging applications include wireless, sub-cellular biosensors that monitor individual health parameters in real-time; techniques for meta-analyses of genetic, biophysical, and behavioral information to inform development of personalized health interventions including therapies; and tailored, broadband, interactive multimedia health communications. What will be the ultimate impact of emerging information and communication technologies on the future of health and health care? It is unclear how these and other upcoming technologies will evolve or how rapidly they will be integrated into health interventions and programs. Undoubtedly, as new eHealth technologies are developed and deployed, our capacity and processes to assess and make informed decisions about their appropriate use will be tested. In the near future, several fundamental societal questions will need to be addressed. What are the policy, ethical, and legal issues around these emerging technologies? Who will have access to cutting-edge technologies? Who will pay and how much? What should be the standards and guidelines for appropriate use of these technologies? What are the implications of these technologies for health care and public health systems in terms of quality, access, and cost? Clearly, the impending availability of enhanced Internet access, innovative interactive tools and devices, integrated health information systems, and gene-based screening, diagnostic tools, and therapy, will force further public debate about the central issues of quality, privacy and confidentiality, clinical appropriateness, public policy, cost and financing, and resource distribution.

Return to Top



Foreword

**Preface** 

Acknowledgements

Executive Summary

**Introduction** 

Current Status of the eHealth Sector

Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

What is eHealth? What is the Role of eHealth in Health and Health Care? Who is Using the Internet and Online Health Resources?

We are witnessing an unparalleled era of discovery and innovation. Recent advances in information and communication technology have compelled us to rethink how we work, play, and relate to other people. For instance, the information contained in the entire collection of the Library of Congress can be transmitted in less than 30 minutes; 450,000 people can have a simultaneous telephone conversation via the Internet— all through a glass fiber smaller in diameter than a human hair (Alcatel, 2000). In 1998, the United States Postal Service delivered about 101 billion pieces of mail compared to at least 618 billion email messages exchanged (U.S. Internet Council, 1999). By 2005, about 35 billion emails will be sent daily worldwide (IDC, 2000a). In addition, people have access to the largest volume of health information in history. People can seek support and advice from potentially millions of online peers and professionals worldwide at any time of day. Using the Internet, they can also assess their health risks, fill a prescription, manage a chronic condition, decide on treatment regimens, and consult a health care provider without leaving their home. Emerging information and communication technologies promise to usher in a wealth of innovative solutions for seemingly intractable problems in health and health care, including quality, access, and cost.

Against this backdrop of unprecedented technological innovation, many aspects of the health and health care systems are in need of serious attention. These systems are ripe with inefficiencies, inequities, and errors. The United States spends more on health care than any other country. Health care spending, approximately \$1.1 trillion (13.5 percent of GDP) in 1998, is projected to reach \$2.2 trillion (16.2 percent of GDP) by 2008 (Levit et al., 2000; Smith et al., 1999). About a quarter of this expenditure may be attributed to administrative inefficiencies and waste. Employer health care costs are growing at record rates. Despite the enormous health care investment, more than 44 million Americans, including 11 million children, do not have health insurance (U.S. Census Bureau, 1999). In addition, between 44,000 and 98,000 people may die every year as a result of medical errors (Institute of Medicine, 1999), and variations in medical practice may result in uneven patient outcomes (O'Connor et al., 1999). Increasingly, people perceive that they are ceding control of their health care decisions to institutions that have placed financial priorities above individual health needs. Paradoxically, clinicians are

under increasing pressure to do more with less. Both consumers and health professionals feel overloaded by the tremendous volumes of health information produced by research— an issue that will be exacerbated by continuing advances in growing fields, such as genetics. Although Americans have recently made inroads in some behaviorlinked conditions, such as tobacco use and teen pregnancy, other health problems, such as physical inactivity and obesity, are at epidemic levels.

eHealth technologies, if appropriately implemented, offer promising solutions to longstanding national and global health problems. This document provides a broad overview of the emerging field of eHealth, and highlights areas that may be leveraged to help ensure that this emerging discipline will exert a positive impact on health and health care. This report describes how the Internet is being used in the health sector, and outlines commercial and publicly sponsored eHealth activities, major policy issues, concerns and potential pitfalls of eHealth, and emerging trends in technology and their implications for future eHealth tools.

# The following questions are addressed in this report :

- What is the emerging field of eHealth?
- Who are the major players in this dynamic arena?
- What are the major eHealth issues?
- What are the emerging trends and technologies on the immediate horizon that will shape future eHealth tools?

Return to Top

# WHAT IS eHEALTH ?

eHealth is the use of emerging information and communication technology, especially the Internet, to improve or enable health and health care.

The term "eHealth" has evolved into the dominant term used by the Information Technology (IT) industry and mass media to describe this area. It was derived from the term "electronic commerce" ("eCommerce"), which was coined in the mid-1990s to reflect the expanding commercial use of the Internet. In addition to eHealth, other terms have been widely used in the past several years to describe the application of information, computer, or communication technology to some aspect of health or health care. These terms include medical informatics, consumer health informatics, public health informatics, telemedicine, telehealth, and interactive health communication. There is some confusion in the field because recognized experts define many of the above terms differently and some terms have overlapping concepts. However, if one adopts a broad definition of eHealth— the use of emerging information and communication technology, especially the Internet, to improve or enable health and health care— it could be argued that eHealth is the appropriate umbrella term that encompasses the other concepts.<sup>2</sup> Thus, "eHealth" is used in such a context in this document. The term bridges both the clinical and nonclinical sectors and includes both individual and population health-oriented tools. eHealth may also be the preferred term because it is widely accepted by the IT industry, the mass media, and some segments of the general public. Figure 1 illustrates a perspective on how several components of eHealth relate to one another.

The field of eHealth may be best explained by considering the specific functions and capabilities of eHealth technologies. Several eHealth analysts have structured the field by using anywhere from a three to five "C's" framework. <u>Table 1</u> shows how the various functions and capabilities of eHealth tools could be framed using a content, connectivity, community, commerce, and care model. It should be noted that the categories presented are not mutually exclusive; in fact, there is considerable overlap among them, and many online applications fit in several categories and perform multiple functions. <u>Table 2</u> presents a short description of each function and capability, including illustrative examples for each category.

# FIGURE 1 Relationship Between Various Components of eHealth.



*Note:* Interactive health communication includes areas of all the above disciplines (Science Panel on Interactive Communication and Health, 1999).

# **EXAMPLES OF OVERLAP:**

- A = population health tools
- **B** = health promotion/disease prevention tools
- C = shared clinical decision-making tools

#### Return to Top

# TABLE 1Functions and capabilities of eHealth under the 5 "C's"model.

# CONTENT

- Information presentation
- Information search assistance
- Health behavior change
- Informed decision-making
- Distance learning and training

# CONNECTIVITY

- Clinical and public health information systems
- Health services and systems integration
- Administrative transactions
- Clinical and biomedical research

# COMMUNITY

• Peer-to-peer and person-to-person messaging, information exchange, emotional support, and community building

# COMMERCE

• eCommerce and shopping

# CARE

- Self-care
- Care coordination and information portability
- Electronic health records
- Shared clinical decision-making
- Expert systems
- Disease management
- Telemedicine/telehealth

Return to Top

# TABLE 2 Functions, capabilities, and examples of eHealth tools.

ТҮРЕ	FUNCTIONS AND CAPABILITIES	EXAMPLE(S) OF TOOL/APPLICATION
Information presentation	Provide general or individualized health information on demand.	www.healthcentral.com www.healthfinder.gov www.mayohealth.org www.oncolink.com www.webmd.com

Information search assistance	Help locate online content and other resources in response to a specific information request through search engines, directories, personalization technologies, or intelligent systems.	www.bmn.com (Biomednet) www.medweb.emory.edu/MedWeb (MedWeb) www.medmatrix.org www.ncbi.nlm.nih.gov/PubMed/ (PubMed) www.ohsu.edu/cliniweb/ (Cliniweb International)
----------------------------------	--	---

Health behavior change	Promote the adoption and maintenance of positive health behaviors on both an individual and community level. Some applications promote healthy behaviors by providing information, assessing risks, explaining associated benefits and costs, and facilitating peer support. These tools may be based on theories of behavior change.	www.eatright.org (American Dietetic Association) www.hc-sc.gc.ca/hppb/ (Health Promotion Online) www.shapeup.org (Shape Up America)
------------------------	---	--

Informed decision- making	Facilitate the decision-making process of individuals (e.g., consumers, patients, caregivers, family members) regarding the prevention, diagnosis, or management of a health condition or the selection of a provider or service.	www.cancerfacts.com www.emedicine.com www.healthgrades.com www.medicare.gov/mphCompare/ (Medicare Health Plan Compare) www.medicineonline.com www.respectprotect.com (Illinois Department of Public Health)
Distance learning and training	Facilitate the learning and training process among instructors and students who are located in different places.	www.cmeweb.com www.cdlhn.com (California Distance Learning Health Network) cdlhc.sph.unc.edu/cdlhc.cfm (University of North Carolina School of Public Health Center for Distance Learning) www.medschool.com
Clinical and public health information systems	Support the routine work processes of clinicians (e.g., clinical, lab, reimbursement) and public health professionals (e.g., surveillance, outbreak investigation).	www.abaton.com www.cerner.com www.idx.com www.medicalogic.com www.phppo.cdc.gov/han/ (Health Alert Network)

Health services and information systems integration	Promote integration and interoperability of services or information systems across health sectors.	www.allkidscount.org www.mahealthdata.org (Massachusetts Health Data Consortium) www.mhdi.org (Minnesota Health Data Institute)
<i>Administrative</i> <i>transactions</i>	Facilitate online transactions and administrative functions (e.g., appointment scheduling, eligibility and enrollment, financial transactions).	<u>www.kponline.org</u> (Kaiser Permanente)
Clinical and biomedical research	Facilitate clinical trials and other biomedical research.	www.centerwatch.com (Center Watch Clinical Trials Listing Service) www.ncbi.nlm.nih.gov/Genbank (Human Genome Project's Genbank) www.sciencewise.com
Peer-to-peer and person to-person messaging, information exchange, emotional support, and community building	Enable individuals (e.g., consumers, patients, health professionals, caregivers) with specific health	www.acscsn.org (Cancer Survivors Network) <u>chess.chsra.wisc.edu/Chess/</u> (Comprehensive Health Enhancement Support System) <u>www.quitnet.org</u> Various listservs, Usenets, chat

conditions,

perspectives to communicate and

information, and

needs, or

share

Various listservs, Usenets, chat channels on health (see www.liszt.com)

	provide or receive peer and emotional support. There are online support groups and virtual communities for virtually all health conditions.	
eCommerce and shopping	Enable online purchase of health-related goods and services, including medications and personal care products, health insurance, books, and other products.	www.drugstore.com www.ehealthinsurance.com www.medibuy.com www.webrx.com
Care coordination and information portability	Facilitates case management and information exchange across the continuum of care.	www.canopysystems.com www.per-se.com
Electronic health records	Support the storage and retrieval of computer-based personal medical and health data.	www.personalmd.com www.wellmed.com

Shared clinical decision-	Assist clinicians	www.healthdialog.com
making	and patients to	
	jointly evaluate	
	and decide on a	
	course of	
	treatment based	
	on current	
	evidence, likely	
	outcomes, and	
	patient	
	preferences (a	
	subset of	
	informed	
	decision-making	
	tools).	

Expert systems	Guide clinicians or other professionals in making screening, diagnosis, or treatment decisions based on accepted standards of practice.	www.epocrates.com www.ncemi.org (National Center for Emergency Informatics)
	Assist movidors	www.coordont.com

Disease management	Assist providers	www.accordant.com
	and others to	www.alere.com (Alere Medical)
	reduce	www.ecorsolutions.com
	unnecessary or	www.lifemasters.com
	inefficient patient	www.thedailyapple.com (Caresoft)
	use of health	www.medanyupple.com (Caresolt)
	services and/or	
	increase use of	
	effective services	
	(some overlap	
	with self-care	
	tools).	

Telemedicine/telehealth	Support the delivery of clinical services or selected elements thereof.	www.axolotl.comwww.dod-telemedicine.org(Department of DefenseTelemedicine)www.etherapy.comwww.hhn.com (Health HeroNetwork, Inc.)www.mdexpert.com
-------------------------	---	--

Return to Top

In addition to the primarily Web-mediated applications described in Table 2, other Internet-based technologies have health-related applications, including newsgroups, listservs, chat rooms, messaging, and virtual communities and virtual worlds.

Usenets, or "newsgroups," were introduced in the late 1970s and are essentially Internet bulletin boards that allow users to read and post information about a particular subject, including health (e.g., <u>www.cyberfiber.com/index.html</u>, <u>www.tile.net</u>). Newsgroup postings are typically asynchronous (not real-time).

Listservs automatically deliver email to and from subscribers of a mailing list, which is organized around a specific topic or interest group. An electronic registry manages the list of subscribers. Some listservs restrict membership and some are moderated. In health, disease-specific listservs, such as for cancers (e.g., www.oncolink.upenn.edu/forms/listserv.html) are extremely popular among consumers. Professional– and consumer-oriented listservs are available for virtually any health condition or issue (e.g., www.liszt.com, www.lsoft.com/lists/listref.html).

Internet Relay Chat (IRC) was introduced in the late 1980s and is similar to realtime newsgroups. It has become an extremely popular method for multiple-user, text-based, real-time chat on the Internet. Under this system, IRC networks host hundreds to thousands of "channels" on different topics, including health (e.g., <u>www.liszt.com/chat/</u>). In some cases, access to chat sessions may be restricted and/or moderated.

Instant messaging is a more recent Internet technology than IRC. This type of software alerts users when other users they know are online (e.g., "buddy lists") and allows them to communicate in real-time. Chat sessions with multiple users and file sharing are also supported, but current versions of messaging software are not interoperable. AOL dominates the instant messaging world with more than 150 million users after their recent purchase of a popular rival product, ICQ. Instant

messaging applications for health abound (e.g., <u>www.icq.com/networks/HealthandMedicine/</u>), and are increasingly being ported to non-PC devices, such as wireless phones and digital pagers.

Virtual communities are established around specific topics or interest areas, and typically incorporate real-time communication channels, such as instant messaging, and/or asynchronous communication methods, such as email and newsgroups. Examples of Web sites that support virtual communities in health and other areas include iVillage (www.ivillage.com), Geocities (www.geocities.com), and Tripod (www.tripod.com).

Virtual worlds are recent multimedia-based versions of virtual communities. People use real-time communication technologies to meet and communicate in a virtual space through avatars, which are 2D or 3D graphical representations of themselves. Examples of multi-user virtual worlds include Planet 9 (www.planet9.com), and DigitalSpace (www.digitalspace.com). Although most virtual world projects are currently entertainment – or business-oriented, the technology may have important applications in health, especially in telemedicine and health communication (Marsh et al., 1999). Virtual Private Networks (VPNs) are Internet-based networks that use encryption and tunneling to connect multiple organizations or parts of organizations; thus, potentially saving costs associated with Wide Area Networks (WANs) and dedicated data lines. VPNs can be used as a point of access to intranets, extranets, and the Internet. In the eHealth arena, VPNs could be applied to facilitate a range of clinical and nonclinical enterprises (e.g., www.ehealthline.com, www.ehealthengines.com).

Return to Top

# WHAT IS THE ROLE OF eHEALTH IN HEALTH AND HEALTH CARE?

The overriding considerations for the health care and public health systems in the United States today are quality, access, and cost. The extent to which an eHealth tool can effectively address one or more of these key elements may ultimately determine its value, and whether it will be widely adopted in the marketplace.

After the failure to ensure universal health care coverage in the mid-1990s, much of the nation's focus has shifted to the issues of quality assurance and controlling health care costs (Chassin et al., 1998). Concomitant with this interest, emerging information and communication technologies have greatly facilitated the collection, interpretation, and dissemination of quality– and cost-related data. Several components of quality assurance, such as measuring and monitoring outcomes, are

by nature data intensive, and require robust and scalable eHealth solutions. The use of Internet-based tools in quality assurance and measurement is only in its infancy stages (Bates and Gawande, 2000). Recently, the reduction of medical errors has received considerable attention as a national priority (Institute of Medicine, 2000). Many eHealth developers are responding to this problem by offering a growing number of eHealth tools, such as wireless expert systems, that are deployed at the point of care. eHealth content portals are quickly striving to fulfill consumers' desire for unabated access to information. In the area of enhancing access to health services, telemedicine and telehealth programs have been successfully deployed in rural and other medically underserved areas. In addition, many eHealth tools address the need to contain or reduce health care costs. Examples of these tools include applications that improve the efficiency of administrative transactions through electronic platforms, virtual marketplaces (business-to-business and business-to-consumer) that minimize or eliminate costs associated with intermediaries, and online disease management and self-care tools that promote appropriate use of health services and discourage unnecessary health care visits.

#### Return to Top

# WHO IS USING THE INTERNET AND ONLINE HEALTH RESOURCES?

- Approximately 60 percent of the total U.S. population had access to the Internet in January 2001, and as many as 86 percent of adult Internet users accessed it to research information on health care or specific diseases.
- The number of health-related Web sites available is unknown, but it is widely believed that the more than 19,000 health sites indexed on Yahoo! as of May 2001 represent only a small fraction of the universe of eHealth sites.

More than 400 million people worldwide had access to the Internet at the end of 2000 (NUA, 2000). In January 2001, about 169 million Americans (60 percent) had Internet access from home or work (Nielsen//NetRatings, 2001). The most common reasons why Americans use the Internet are to obtain information (95 percent), to send or receive email (89 percent), to shop (45 percent), and to visit chat rooms (21 percent) (NUA, 2000).

Use of online health resources has grown dramatically in the last few years. Estimates of health-related Internet use vary greatly, but a mid 2000 survey estimated that as many as 98 million Americans or 86 percent of adult Internet users employed it to research information on health care or specific diseases, up from 71 percent in 1998 (Harris Interactive, 2000a).<sup>3</sup> About 13 percent of those surveyed reported that they looked at online health information "often," 40 percent looked "sometimes," and 33 percent looked "very occasionally." Another national survey found that most of those who use the Internet for health-related purposes do so at least once a month (Pew Internet and American Life Project, 2000a).

The recent growth in health-related use of the Internet may be explained by the fact that public access to the Internet occurred at a time when people are increasingly more active in managing their own care as well as the care of other family members. In addition, many consumers are increasingly skeptical that health care plans and providers will consistently place their patients' needs ahead of financial or other considerations (Mechanic and Rosenthal, 1999), and are seeking alternative sources of information. According to one survey, a majority of people enrolled in managed care plans report being at least "somewhat worried" that their "health plan would be more concerned about saving money than about what is the best medical treatment" (Kaiser Family Foundation, 1997).

Although populations that have been traditionally underserved are less likely to have Internet access, the profile of Internet users is shifting from one comprised initially of largely white, educated, young men to a much more diverse group of users. In fact, according to an August 2000 survey, the number of women online surpassed that of men for the first time ever in the first quarter of 2000 in the United States (Media Metrix and Jupiter Communications, 2000). In addition, lower-income families still account for a small proportion of all Web users, but they represent the fastest growing segment of new users. In response, a relatively small but growing number of eHealth sites that target specific populations, such as seniors (e.g., www.thirdage.com), Hispanics (e.g., www.salud.com), African Americans (e.g., www.blackhealthnetwork.com, www.blackmenshealth.org), are becoming available.

The Web represents the largest "collection" of documents in history, but it is unclear exactly how many unique Web pages exist. One company estimated that there were more than one billion unique documents posted on the Web on a total of 4,951,247 unique servers at the end of 1999 (Inktomi, 2000). Publicly indexed pages, however, are only the tips of the information iceberg. One company, for example, estimates that the "deep Web," which are pages in about 100,000 publicly available Internet databases, may contain 7,500 terabytes of information, compared to 19 terabytes of information in the "surface Web" (BrightPlanet, 2000). That is, the "deep Web" may have nearly 550 billion individual documents, most of which are in topic specific databases, compared to the 1 billion or so documents on the "surface Web."<sup>4</sup>

The size of the Web is now so large that it has surpassed our ability to make use of all the information contained in it. An analysis of the Web in February 1999 found that the most comprehensive search engine was only able to search about 16 percent of the total pages available (Lawrence and Giles, 1999). The number of health-related Web sites available is unknown, but it is widely believed that the more than 19,000 health sites indexed on Yahoo! as of May 2001 represent only a

small fraction of the universe of eHealth sites for the reasons above. In addition, the number of eHealth sites and databases will continue to grow dramatically as emerging technologies, such as genomics, produce staggering volumes of new health information. Approximately 86 percent of Web pages produced are in English (Inktomi, 2000). Nearly 55 percent of domain URLs ended in ".com," 8 percent were ".net," 7 percent had ".edu," 4 percent were ".org," 1 percent were ".gov," and less than 1 percent ended in ".mil" (Inktomi, 2000).

Return to Top

<sup>2</sup> For the purposes of this document, the term "health" refers to all aspects that contribute to the soundness of the body and mind, both on the individual and population levels.

<sup>3</sup> There are many sources of data related to Internet users and usage patterns published by government agencies, nonprofit organizations, and commercial companies. Because published estimates vary greatly from survey to survey, no single study should be viewed as definitive.

<sup>4</sup> These databases comprising the "deep Web" dynamically generate content in contrast to static Web pages.

# CURRENT STATUS OF THE CHEALTH SECTOR

#### **Table of Contents**

Foreword

Preface

#### Acknowledgements

**Executive Summary** 

**Introduction** 

#### Current Status of the eHealth Sector

# Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

#### A Cautionary View of eHealth

#### Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

<u>Commercial Sector Activities</u> <u>eHealth Business Models</u> <u>How Healthy are eHealth Companies?</u> <u>Public Sector and Nonprofit Initiatives</u>

As with other Internet-related sectors, the status of the eHealth arena is extremely fluid and characterized by rapid developments in the commercial and noncommercial sectors. In addition to this document, several online information resources are available to keep up-to-date with recent developments in eHealth (<u>Appendix 1</u>).

# COMMERCIAL SECTOR ACTIVITIES

- The eHealth field has been driven primarily by commercial eHealth companies, some of which have an uncertain future.
- Current eHealth business models are varied and evolving.

Compared to other industry sectors, such as finance and commerce, the adoption and integration of information technology in the health sector is unfolding much more slowly. As with most other Internet-related sectors, the eHealth field is being driven primarily by for-profit eHealth companies. Pure eHealth companies emerged during the mid1990s and many quickly developed dominant positions by relying on heavy marketing to draw a large base of users. <u>Appendix 2</u> summarizes the main characteristics of the eHealth sites with the highest number of users.<sup>5</sup>

Companies ranging from large eHealth corporations to small businesses that employ a few people develop commercial eHealth sites and tools. At present, many of the most recognized eHealth companies are consumer-oriented portals that seek to be "one-stop shops" for health information and health-related products. Many of these health portals sponsor very similar content and tools on their sites. For example, almost all of the most visited health sites have news stories, chat rooms, bulletin boards, "ask the expert" columns, and risk and health assessment tools (Appendix 2). A reason for the similarities is the fact that some business-tobusiness eHealth content providers (e.g., www.healthwise.org, www.adam.com, www.healthscout.com, www.wellmed.com) specialize in developing content and tools and license and customize the content under another company's site or brand. In addition to "pure" eHealth companies, a number of major media companies also offer substantial amounts of health resources (e.g., AOL [www.con.com/webcenters/health/home.adp], Yahoo! [health.yahoo.com], CNN [www.cnn.com/HEALTH], CBS [www.cbshealthwatch.medscape.com], Washington Post [www.washingtonpost.com/wp-dyn/health/]).

The most common focus of larger eHealth companies seems to be on providing tools and solutions, products, or services that support some aspect of clinical care or eCommerce, including administrative transactions, clinical information systems, telemedicine and telehealth, and sales of health-related products. This is because most health-related expenditures in the United States are related to clinical care. With the exception of providing consumers with health information, few companies are focused on populationoriented eHealth tools partly because of perceptions about the viability and scope of this market segment. Because even this level of public health focus is in jeopardy due to the absence of sustainable revenue models, there is a need for public and/or private sector entities to promote development of population-oriented eHealth tools.

Return to Top

# **eHEALTH BUSINESS MODELS**

A business model is the method of generating revenue in order for a company or organization to be sustainable. The business model typically outlines how a company intends to produce revenue by specifying how its products or services will add value to its respective market sector.

A variety of business models are being employed by eHealth entities, including advertising, sponsorship, merchant, transaction fee, licensing, fee-for-service, clinical services, data and infomediary, and subscription models. In some cases, newer eHealth business models may be constrained by existing federal regulations that were designed to prevent provider fraud and abuse (e.g., anti-kickback statute, self-referral/Stark law, beneficiary inducement law) (Fried et al., 2000). The following are the major business models employed by eHealth entities, both commercial and nonprofit. In practice, many companies rely on a combination of the following revenue models.

#### Advertising

The advertising model has its origins in offline mass media where a content producer or aggregator provides content or services (e.g., email reminders, chat rooms, bulletin boards, electronic health record) along with advertising. Advertising can be placed in almost any area of a site or in another medium (e.g., email, chat sessions). In addition to the banner ad, other forms of advertising include placements in facility/provider/service directories, search engine results pages (either through a high ranking or banner ad), pop-up screens, and targeted email content. Web-based banner advertising is typically sold either by "page views" (i.e., how often the ad is viewed by users) or by "clickthroughs" (i.e., how often users click on an ad). For facility/provider/service directories, health care providers and other listed companies may have to pay to be listed or if they receive referrals as a result of the directory listing. The success of the advertising model is extremely dependent on the traffic volume generated or the specialized nature of the target audience. All of the major commercial health portals have advertising revenue. Many market analysts believe that sole reliance on advertising revenue is not sustainable for any but a handful of the largest sites. One reason is that advertisers are disappointed in low click-through rates. Also, much of the "revenue" reported by eHealth companies represented barter revenue rather actual cash proceeds.

# Sponsorship

In the commercial sponsorship model, sites seek core sponsors who pay a fee to have access to prime advertising opportunities and may serve as advisors to the company. Sponsors may also "co-brand" the site. Prime examples of major eHealth sponsors are pharmaceutical companies and retailers, such as pharmacies (e.g., WebMD and CVS.com co-branding). In many cases, however, "sponsorships" are actually sales of stock. Some sponsor agreements have included the ability for the sponsor to provide or influence site content.

In the community and public sponsorship model, nonprofit eHealth sites rely on voluntary contributions (financial or in-kind) from dedicated users. Some nonprofit eHealth sites, especially those that target highly specialized interest groups or provide services for the public good, rely on funding from corporate sponsors and charitable foundations. Examples of foundations that appear to have an explicit interest in sponsoring information and communication technology activities are available in <u>Appendix 3</u>. Government-sponsored eHealth sites are supported exclusively by agency budgets. Some commercial and nonprofit sites have affiliate agreements with online merchants, whereby the site refers purchasers to the merchant through banner ads, and collects a small percentage of the purchase.
#### Merchant

Within the revenue model, income is generated from the online sale of healthrelated products directly to consumers. Virtually any health-related product available through physical stores are available online. Products may be sold at a specified price or through auction. Online merchants can be "pure" Internet companies (e.g., <u>www.webrx.com</u>, <u>www.drugstore.com</u>) or may also have physical retail stores (e.g., <u>www.CVS.com</u>, <u>www.walgreens.com</u>). Often, products directly related to health are marketed along with ancillary items or services (e.g., "health & beauty," services for people with special health needs).

#### **Transaction Fee**

Transaction fees are typically garnered by a company serving in a broker role by bringing buyers and sellers together in the business-to-business (B2B), business-toconsumer (B2C), or consumer-to-consumer (C2C) markets. In a B2B exchange, the company collects a transaction fee based on the value of the sale between buyers and sellers (e.g., <u>www.medibuy.com</u>, <u>www.neoforma.com</u>). In the B2C segment, sites enable consumers to compare and purchase products and services, such as health insurance or clinical services for individuals (e.g., <u>www.medicineonline.com</u>). Some sites also aggregate individual online buyers so that they can collectively purchase products at a volume discount (e.g., <u>www.accompany.com</u>). Other sites sign up online merchants to occupy "virtual malls" for a listing or transaction fee (e.g., Yahoo! Shopping, <u>www.ehealthconnection.com</u>). In the C2C (and B2C) market, a broker receives a fee for facilitating the auction (e.g., <u>www.ebay.com</u>). In addition, other sites allow customers to name their own price and/or requirements for goods and services (e.g., <u>www.medicineonline.com</u>).

## Licensing

Licensing is when a business provides another company with the right to use a product under certain terms for a fee. Several eHealth companies specialize in developing content brand. Examples of licensed products include clinical information systems, administrative systems, and online disease monitoring and disease management services. These are often licensed to health plans or employers, which in turn provide them to enrollees and employees (e.g., www.bestofhealth.com, www.pdhi.com, www.wellcoaches.com). Licensing is the most common revenue model for Application Service Providers (ASPs), which are companies that provide online software applications and/or software-related services to other businesses. ASPs are discussed in detail later in this document.

## Fee-for-Service

This is when a company provides some type of service online to consumers, professionals, or businesses for a fee. Examples of eHealth-related online services include survey and marketing research, clinical trial recruitment for pharmaceutical companies, and customized advice and research services (e.g., www.americasdoctor.com, www.clintrialsresearch.com, www.harrisinteractive.com).

## **Clinical Services**

Some eHealth sites provide clinical consultations on a fee-for-service basis (e.g., <u>www.doctorglobal.com</u>, <u>www.thedoctoronline.com</u>). Specific types of services may be reimbursable depending on the payor. Although clinical services that rely on physical exams and diagnostic tests are rarely conducted online through the public Internet, tools that facilitate follow-up clinical care (e.g., disease management) and mental health services and counseling, are increasingly available (e.g., <u>www.helphorizons.com</u>, <u>www.here2listen.com</u>). Other tools support selected aspects of clinical care, such as secure messaging between providers and patients (e.g., <u>www.healinx.com</u>, <u>www.axolotl.com</u>).

#### Data and Infomediary

A company collects and organizes data obtained online and packages and sells this aggregate data (stripped of personal identifiers) to other businesses, usually for market research purposes. The type of data collected online includes information provided by site visitors, data on online purchases, data on user patterns from tracking software, and aggregated health data gleaned from transactions and electronic health records (e.g., <u>www.i-trax.com</u>, <u>www.netzero.com</u>).

#### **Subscription**

Subscription is when users pay for site access or access to premium content. This strategy is rarely successful for eHealth companies given the volume of free online health content. Only sites with unique or proprietary content (e.g., www.ediets.com, www.consumerreports.org, www.wsj.com) use this model.

In addition to the business models described above, some companies and organizations, such as traditional ("bricks and mortar") health care delivery systems, may invest in eHealth technologies without the expectation that such initiatives will represent substantial sources of revenue.

## These reasons include:

- *Operational efficiencies.* eHealth technologies may enable an organization to provide services of equal or greater quality at less cost (e.g., automated prescription ordering and refills, electronic messaging instead of mailings).
- *Member/client growth and retention*. Effective eHealth services may enable a health plan or care provider to attract new customers and retain them longer, thereby eventually increasing revenue from dues and fees.
- *Cost of doing business.* Some organizations are investing in eHealth technologies simply because they have determined that a minimal level of investment is necessary in order to provide service to customers and to stay competitive in the information age economy.

#### Return to Top

## HOW HEALTHY ARE eHEALTH COMPANIES?

• The long-term outlook for publicly traded eHealth companies is unclear. However, the recent Internet stock market correction suggests that some eHealth companies will fail, fewer eHealth companies will be going public in the next few years, and venture capital will be more difficult to obtain, which may put new eHealth companies at a severe disadvantage in raising capital.

Private sources of financing for start-up eHealth companies include self-financing, family and friends, angel investors, financial institutions, venture capital firms, and corporations. Several venture capital firms either specialize or have major investments in eHealth companies (Appendix 4).

When the first pure eHealth companies went public, many of them were caught up in the Internet investment mania of the late 1990s. As a result, many eHealth companies were quickly valued at extremely large valuations by the stock market. When technology stocks suffered a large correction in the spring of 2000, eHealth and other Internet stocks, especially those that had a business-to-consumer business model, underwent severe corrections (Robinson, 2000). For example, the market capitalization of drkoop.com dropped from about \$1.4 billion at the peak of its stock price to less than \$10 million (< 1 percent of peak value) at its lowest price level as of May 2001.

Investment professionals and the public are currently avoiding those companies that do not have profits or a good likelihood of attaining profits in the near future. As a result, Internet companies that have relied on spending exorbitant amounts of marketing funds to attract and retain users, including many eHealth consumer information and retail sites, have dropped out of favor. The long-term outlook for publicly traded eHealth companies is unclear but the recent Internet stock market correction suggests that fewer eHealth companies will be going public in the next few years, and that venture capital will be more difficult to obtain.

If the stock market and other large sources of financing continue their general skepticism of the eHealth sector, new eHealth companies will be at a severe disadvantage compared to large corporations that have substantial capital reserves. Several large technology corporations have taken a specific interest in eHealth. Perhaps the most notable of these corporations is Intel, which seeks to promote the development and adoption of eHealth applications through their Internet Healthcare Initiative (www.intel.com/intel/e-health/index.htm).<sup>6</sup> In addition, it should be recognized that much of the technical innovation required for eHealth applications is accomplished by large technology companies (e.g., EMC, IBM, Microsoft, Oracle, Sun Microsystems), whose products and platforms are used by many sectors, including health.

During the last few years, traditional ("bricks and mortar") health corporations, which were initially slow to embrace the Internet, have become increasingly active in Internet-related ventures. As with many other sectors, such as retailing, traditional large health-related corporations, including pharmaceutical and health care companies, will increasingly enter the eHealth arena and compete or partner with or purchase smaller Internet-focused companies in the next several years (Robinson, 2000). Of these large corporations, pharmaceutical companies, in particular, have substantial amounts of capital and will be increasingly active in eHealth activities, both for marketing initiatives, such as direct-to-consumer advertising, and for investment purposes. For example, Merck recently announced the creation of a venture fund that will provide up to \$100 million to new eHealth and other health technology companies (Merck, 2000). In addition, PacifiCare Health Systems, one of the largest managed care companies in the United States, recently created their PacifiCare Ventures division, which seeks to increase the company's involvement in eHealth through joint ventures and capital investments. Because access to capital and a large user base remain critical for most eHealth companies, it is likely that "pure" publicly traded eHealth companies will become increasingly rare and many of these companies will eventually be wholly or partly owned by large health- or technology-related corporations.

Regardless of the outcome of the competition between traditional health-related corporations and Internet-centric companies, it is likely that considerable eHealth

application development will continue among small business entrepreneurs. Although these small companies may not be large enough to be detected on the "radar screens" of large corporations and investment firms for many years, they will likely remain a major location for innovation in the eHealth field.

#### Return to Top

## PUBLIC SECTOR AND NONPROFIT INITIATIVES

- Many federal agencies, particularly agencies under the U.S. Department of Health and Human Services, and nonprofit organizations sponsor eHealth-related initiatives.
- It is possible that nonprofit and public sector eHealth entities will gain market share going forward, and many nonprofit organizations, especially professional societies and universities, have developed formal partnerships with commercial companies.

There is no federal eHealth coordinating agency or government-wide strategic plan for eHealth, nor is there a comprehensive inventory of federally sponsored eHealthrelated programs, except for a review of federal telemedicine programs (Health Resources and Services Administration, 1998). Accordingly, observers have called for stronger federal leadership in eHealth issues (Shortliffe, 2000).

Several federal agencies sponsor eHealth-related initiatives. All of the agencies within the U.S. Department of Health and Human Services have Web sites that disseminate information about agency-specific initiatives, and some also have portal sites similar, from a content perspective, to those of commercial health sites (e.g., <u>www.healthfinder.gov</u>, <u>www.medlineplus.gov</u>, <u>www.4woman.gov</u>). Although the number of users of government-sponsored eHealth sites is relatively low compared to the top commercial sites, several government sites have become quite popular with the public and with health professionals. In fact, the National Institutes of Health's (NIH) site (<u>www.nih.gov</u>) is often listed among the top ten most visited eHealth sites.

During the last several years, government agencies have been making health information and publications readily available on the Web. In addition to federal agencies, state and local health jurisdictions have been steadily increasing the variety of online information. For example, the Missouri Department of Public Health's Web site allows users to generate customized community health data tables (<u>www.health.state.mo.us</u>), and the New York City Department of Health has posted restaurant inspection results online (<u>www.nyc.gov/html/doh/html/rii/index.html</u>).

The federal government is also providing online research tools for specific professional and scientific communities. One of the most notable of these efforts is the online database associated with the Human Genome Project, Genbank (<u>www.ncbi.nlm.nih.gov/Genbank</u>), which allows scientists to transmit and retrieve updated DNA sequencing data on a daily basis (National Center for Biotechnology Information, 2001).

Many of the public health-oriented federal initiatives are primarily sponsored by the Centers for Disease Control and Prevention (CDC), and include the Information Network of Public Health Officials, the Health Alert Network, EpiX, and the National Electronic Disease Surveillance System (NEDSS). The Health Alert Network is developing infrastructure to enable rapid response to bioterrorism and other public health emergencies (www.phppo.cdc.gov/han/); EpiX is creating a tool to enhance communication about epidemics; and NEDSS seeks to dramatically improve the national surveillance system for reportable diseases (CDC, undated).

Several federal agencies have substantial telemedicine and telehealth activities (Darkins and Cary, 2000). The Department of Defense is the leading federal agency in the use of and investment in these technologies (www.dod-telemedicine.org). Other agencies that have a substantial portfolio of activities in the telemedicine and telehealth areas include NASA (www.hq.nasa.gov/office/olmsa/aeromed/telemed/), the Veterans Administration (www.va.gov/telemed/), and the Health Resources and Services Administration, whose Office for the Advancement of Telehealth (telehealth.hrsa.gov/) facilitates telehealth services in rural areas and community health centers.

The two major federal agencies with regulatory authority over eHealth matters are the Federal Trade Commission (FTC) and the Food and Drug Administration (FDA). The FTC has taken action in cases of fraudulent online marketing of health care products (FTC, 1999), and the FDA has jurisdiction over the online marketing and sale of pharmaceuticals and medical devices.

Federal funding of eHealth projects is available in the form of grants and contracts for research, demonstration projects, and application development. Public funding in the form of competitive Small Business Innovation Research (SBIR) grants and contracts are available for R&D efforts by small eHealth companies. The SBIR program was started in 1982 to promote the development and commercialization of technology-based products by small businesses. The primary sponsors of healthrelated SBIR awards are the NIH Institutes, which budgeted approximately \$352 million for their SBIR programs in fiscal year 2000 (NIH, 2000). The proportion of funds awarded to eHealth-related proposals is unclear. The Department of Commerce, through the Technology Opportunities Program (formerly known as the Telecommunications and Information Infrastructure Assistance Program), was an early mover in funding telehealth demonstration projects (www.ntia.doc.gov/otiahome/top). Approximately \$12.5 million was available for grants in fiscal year 2000. Biomedical research grants have also been awarded typically to university groups working on eHealth-related issues, but most of these projects have a focus on research and evaluation rather than on application development. In terms of research funding, the NIH Institutes, especially the National Cancer Institute, the National Heart Lung and Blood Institute, and the National Library of Medicine, have been most active in funding eHealth-related proposals. The National Cancer Institute has recently launched a major effort to promote the use of emerging technologies to improve cancer-related communications efforts. The National Library of Medicine (NLM) has been active in funding projects to enhance consumer and health professional access to online resources among health institutions and the public, research on the management and utilization of biomedical information, and graduate training programs in health and medical informatics (www.nlm.nih.gov/nlmhome.html). Less than one year after Medline became freely available online, the number of searches increased tenfold, and 30 percent of users were members of the general public (NLM, 1998).

Important external advisory groups that have provided guidance on eHealth and Internet-related issues to the federal government include the National Committee on Vital Health Statistics (NCVHS), which advises the Secretary of Health and Human Services and Congress on health information policy, and the President's Information Technology Advisory Committee (PITAC), which advises the President and Federal agencies on high performance computing, communications, and information technologies. NCVHS has advocated for the development of a national health information infrastructure (NCVHS, 2000a). The PITAC has advocated for strong federal support for research and development of advanced technology applications, development of the national technology infrastructure, addressing the digital divide, and the Next Generation Internet initiative (PITAC, 2001). Another expert committee, the Science Panel on Interactive Communication and Health (SPICH), has documented the science base and policy implications for several aspects of eHealth (SPICH, 1999).

Although most nonprofit health organizations were initially slow in using the Internet to further their charitable missions, many large organizations now have substantial eHealth activities (e.g., <u>www.cancer.org,www.diabetes.org</u>, <u>www.americanheart.org/</u>, <u>www.lungusa.org</u>), and several have developed content and tools that compete with those sponsored by commercial sites. In the long term, it is unclear if the consumer trustworthiness generally afforded to nonprofit organizations and academic institutions is sufficiently persuasive for them to compete effectively with the marketing prowess and quick reaction time of commercial eHealth companies. Beyond the near term, it is possible that nonprofit and public sector eHealth entities will gain market share, but many of these entities may need to revamp their operational procedures to improve customer responsiveness and organizational flexibility. And even nonprofit entities will need to adopt sustainable business models to compete and survive. As a result, many nonprofit organizations and institutions, especially professional societies and academic institutions, have developed formal partnerships with commercial companies, typically as exclusive providers of branded content (e.g., Harvard Medical School and www.intelihealth.com, University of Alabama School of Medicine and <u>www.webmd.com</u>). Some of these organizations realized that joint ventures would enable them to take advantage of the market capabilities and capital of commercial companies and yet retain their nonprofit mission. Another increasingly popular strategy is the formation of for-profit companies or commercial arms by nonprofit organizations. Perhaps the most visible example of this practice in the eHealth arena is the creation of Medem (www.medem.com) by the American Medical Association and several other health care professional societies in 1999.

Nongovernmental organizations have also been playing an important role in eHealth issues, such as research and policy analysis, quality oversight, standards development, and information dissemination. <u>Appendix 5</u> presents an overview of several nonprofit organizations that have funded substantial eHealth-related activities.

Return to Top

<sup>&</sup>lt;sup>5</sup> A comprehensive list of commercial eHealth companies by focus area can be found in Wit Capital. eHealth 2000: Healthcare and the Internet in the New Millennium. New York: Wit Capital, January 31, 2000. Available at:

<sup>&</sup>lt;u>www.witsoundview.com/research/researchbody.jsp?Report=ehlt\_20000131</u>. A more complete list of companies is available at: <u>www.ehealthcarebusiness.com/cda/CompanyDirectory.asp</u>.

<sup>&</sup>lt;sup>6</sup> Intel's eHealth initiative resulted from Andy Grove's (the former chairman of the company) interest in promoting access to online eHealth resources after he was diagnosed with prostate cancer.

# PERSPECTIVES OF MAJOR eHEALTH STAKEHOLDERS

Table of Contents	<u>Consumers</u>
Foreword	Application Developers
	<u>Clinicians</u>
	Policymakers
Preface	Health Care Organizations
	Public Health Professionals
Acknowledgements	Employers and Purchasers

## Executive Summary

**Introduction** 

Current Status of the eHealth Sector

Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

#### Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

Major stakeholders with respect to eHealth development and use include consumers, application developers (creators of eHealth applications and other segments of the IT industry), clinicians, policymakers, health care organizations, public health professionals, employers, and purchasers. Understanding the various motivations and perspectives of these stakeholders is helpful in designing and implementing successful eHealth initiatives. A more in-depth discussion of these and other stakeholder perspectives is available in a series of published articles (Eng et al., 1999; Gustafson et al., 1999; Henderson et al., 1999; Jimison et al., 1999; Patrick et al., 1999).

## **CONSUMERS**

• Consumers are the ultimate drivers in the eHealth arena, but require guidance and tools to help them navigate and select from the growing array of eHealth resources available.

Consumers–who may be healthy individuals, patients, caregivers, or health professionals–are considered by many observers to be the ultimate drivers in the eHealth arena. As users, they will ultimately decide which eHealth sites and tools will succeed or fail. The advent of the public Internet coincided with the emergence of the "empowered" consumer. By disintermediating access to information and tools, the Internet is enabling consumers to remold the traditional clinician-patient (clinician as "authority" model) relationship to a more patient-centered (clinician as "coach" model) one. Using eHealth tools, empowered consumers may be increasingly involved in the clinical decision-making process and demand treatment regimens that take their preferred outcomes into account. In addition to information access and decision support, consumers also look to the Internet for enhanced access to services, greater convenience, and to improved communication with people who are involved in their health care. Provider-patient communication via the Internet, however, is still relatively uncommon. A recent survey revealed that although more than half of the patients wanted to communicate with their providers using email, very few (6 percent) of those surveyed have actually sent an email message to their provider (Sittig et al., 2001).

Consumer demand, along with pressure from payors and the increasingly complex nature of clinical care, may accelerate the Internet-facilitated deployment of standardized health care processes, which may lead to better quality care. On the other hand, it is important to recognize that the Internet has not yet altered the underlying financial incentives and distribution of the health care dollar. This will continue until the traditional decision makers in health care spending (e.g., employers, payors, health plans) make an explicit decision to realign such incentives. From this perspective, consumers' ability to drive many segments of the eHealth sector will be constrained.

One of the major difficulties for many consumers is not so much in finding online health resources, but rather, in selecting the most appropriate ones given their needs from among the hundreds or thousands that appear in a search result. For example, Yahoo! indexes more than 2,000 sites on HIV alone.<sup>7</sup> The growing array of eHealth sites available makes the search process extremely daunting, and many consumers require guidance and tools for appropriate resource evaluation (SPICH, 1999).

A wide array of health-related products from food to medications to health insurance is now available for purchase online. There is no comprehensive, independent, and objective guidance to consumers about online product and vendor selection. Interactive buying guides are available for many consumer products, such as cars, electronics, and other goods (e.g., www.mysimon.com, www.autotrader.com), but tools for supporting more complex purchasing or selection decisions in areas such as health and long-term care insurance and provider selection (e.g., www.insure.com) are limited. Although several federal agencies and states' attorneys general have asserted their roles in online consumer protection, these initiatives are focused on rectifying egregious violations of law rather than on more proactive consumer education.

#### Return to Top

## **APPLICATIONS DEVELOPERS**

• eHealth developers are an extremely heterogeneous group with differing skills and resources, and are under pressure to deliver their products quickly and within budget.

Developers of eHealth resources are an extremely heterogeneous group with differing skills and resources, as mentioned previously. eHealth developers, whether they are commercial companies, nonprofit organizations, or individuals, are typically under tremendous pressure to deliver their products quickly and within budget. This is the norm for the extremely competitive Internet arena. In the commercial sector, the need to be ahead of the competition and the financial pressures to be profitable quickly may result in released products that are not fully bug-free or have not been fully tested and evaluated. Another common dilemma for developers is balancing between investment in marketing and product evaluation. Some products are not evaluated because of time constraints as well as the belief that aggressive marketing efforts may ultimately drive more sales or attract more users than positive evaluation results. For many developers, the competition to obtain capital (i.e., investment funding, grants, contracts) to support development efforts may discourage meaningful collaboration with other developers, potentially resulting in inefficiencies and duplication.

Return to Top

## **CLINICIANS**

• Clinicians are increasingly using the Internet but are not routinely applying eHealth tools in the clinical setting because the Internet does not yet save them substantial amounts of time or money, and may only marginally help them provide better care.

Some health care professionals view eHealth as a threat to the traditional clinicianpatient relationship, where the clinician–especially the physician–is the health information source or intermediary. They are dismayed at the thought of dealing with patients who come to office visits with reams of Web site printouts or who send lengthy email messages several times a week. Other clinicians recognize the fact that advances in biomedical technology and research have moved so fast in the last decade that clinicians cannot keep up with all the latest developments. These clinicians are often willing to help their patients locate and interpret online health resources. They believe that facilitating access to high quality resources helps supplement the information and support provided during an office visit.

Clinicians, traditionally slow adopters of information technology, have gravitated dramatically to the Internet within the last few years. Estimates vary greatly (Chin, 2000), but surveys conducted from 1999 through 2001 show that 70-93 percent of physicians surveyed were using the Internet, with about 40 percent reporting Internet use in the clinical work area and 13-33 percent using email to communicate with patients (Harris Interactive, 2001; Chin, 2001a; Healtheon, 1999). Although most physicians and other clinicians now use the Internet, a much smaller fraction of them have actually integrated the Internet into their practice. One survey found that only about 15 percent of a physician's time online was spent obtaining general clinical information and 8 percent for clinical work relating to their patients (Harris Interactive, 2000b).

Barriers to the adoption of eHealth tools by clinicians include perceived drain on time, legal and liability issues, lack of reimbursement (Kassirer, 2000), and the lack of applications that can be efficiently integrated into a clinician's workflow. The reason clinicians are not routinely applying eHealth tools in the clinic is probably because the Internet does not yet save them substantial amounts of time or money, and may only marginally help them provide better care. Another major reason is that they may not have Internet access at the point-of-care (Handler et al., 1999). A major concern for clinicians is whether they will be reimbursed for Internet-based activities such as patient emails and teleconsultations. At least one group of selfinsured technology companies and one managed care organization is reimbursing for Internet consultations between patients and their network physicians (Chin, 2001b; Healthcare Informatics, 2000). Reimbursement for Internet-based services would undoubtedly be a strong incentive for clinicians to better integrate technology into their practice, but, ultimately, eHealth tools, such as decision support aides, need to be available at the point-of-care and integrated into the clinical workflow before they become widely used. Emerging wireless devices promise to address some of these issues.

#### Return to Top

## POLICYMAKERS

• Both public and private policymakers, through legislation and regulatory initiatives and through purchasing, investment, and implementation decisions, respectively, determine the context in which eHealth applications

are developed and deployed.

By virtue of their decisions, policymakers determine the context in which eHealth applications are developed and deployed. In developing legislation and regulations, public policymakers balance the uncertainties associated with voluntary industry standards and self-regulation with more direct, but often unpopular, legislative and regulatory options. Major issues of concern to policymakers include ensuring quality, consumer protection against online fraud and misleading information, access and the digital divide, reimbursement for online services, and the ultimate impact of eHealth on health and health care systems. Although there is no official entity with a mission to develop and implement public policy for eHealth, several types of public and private policymakers are involved in setting eHealth policy.

In the public sector, several government agencies have a major role in eHealth policy given their mandate to promulgate regulations governing related areas, such as data security (e.g., Health Insurance Protection and Portability Act regulations by the U.S. Department of Health and Human Resources), consumer protection and fraud (e.g., Federal Trade Commission), and approval and sale of prescription drugs and medical devices (e.g., Food and Drug Administration).

In the legislative arena, Congress has demonstrated keen interest in a number of policy issues. The most popular Internet-related legislative initiatives in recent years include efforts to prevent access to materials that are considered to be "harmful to minors," to protect privacy and security of personal data collected online, to clarify standards for online monitoring by law enforcement officials, to clarify digital copyright and trademark issues, and to increase access to broadband Internet access (www.cdt.org/legislation/, www.techlawjournal.com, Smith, 2000). Recently enacted bills that have some implications for eHealth, include the Children's Online Protection Act, which requires content providers who disseminate material that is "harmful to minors" to take certain steps to restrict access to such materials by minors under age 17, and the Children's Online Privacy Protection Act, which requires Web site operators to obtain verifiable parental consent before collecting, using, or disseminating information about children under age 13. There has been considerable concern that some types of legitimate eHealth content (e.g., information about obstetrics and gynecology, sexually transmitted diseases) could be blocked by bills designed to restrict minors' access to adultoriented materials. Not surprisingly, some enacted privacy legislation has been successfully challenged in the courts.8

In the private sector, health care executives and large employers essentially set eHealth policy in their organizations by virtue of their purchasing and implementation decisions, which ultimately determine whether specific eHealth applications are deployed and adopted. Government purchasers of health services, such as the Medicare and Medicaid programs, have substantial impact on the adoption of eHealth applications through their reimbursement guidance. Other corporations including financial and investment companies essentially determine which eHealth technologies will have the financial resources to explore developing their niche in the market.

In addition, professional societies, such as the American Medical Informatics Association (www.amia.org), the Institute of Electrical and Electronics Engineers (IEEE) (www.ieee.org), and the Internet Society (www.isoc.org), often issue position statements and propose standards that have influence over the development and use of eHealth tools. In the global arena, the Internet Corporation for Assigned Names and Numbers (ICANN) (www.icann.org) has responsibility for managing the assignment of Internet Protocol (IP) addresses and domain name registration.

Return to Top

## **HEALTH CARE ORGANIZATIONS**

• Many large health care organizations have sizable capital investments in legacy systems and may be somewhat reluctant to transition to Internet-based solutions.

Large health care organizations, such as health plans, hospital systems, and provider groups, have been longstanding users of clinical and administrative information systems. As a result, many of these institutions have sizable capital investments in legacy systems and may be somewhat reluctant to transition to Internet-based solutions. Much of the electronic information exchange among health care providers, payors, laboratories, and reporting agencies (e.g., disease or trauma registries) is still conducted in a batch mode format rather than in an interactive, Web-enabled manner. This may remain the case for several more years. Another impediment to the adoption of eHealth tools stems from the independent operating and competitive nature of many health care organizations, which may not see the need to share information with other institutions. In addition, in the current context of narrow profit margins, many health care organizations are unable or reluctant to commit substantial resources for new information technology investment. With respect to implementing eHealth tools, health care organizations will look favorably upon those that are effective in improving patient care, managing demand for services, retaining beneficiaries, and improving their relationship with network or staff clinicians.

Some health plans are beginning to provide and encourage beneficiary use of

Internet-based tools. For example, Kaiser Permanente is spending \$2 billion on a variety of technology investments over the next five years to "become the most wired health plan in the country" and hopes to eventually eliminate paper-based transactions (Atlantic Information Services, 2000). Health plans that ignore eHealth technologies may risk disintermediation if employers and others adopt new provider network models that bypass the functions of health plans (e.g., www.vivius.com) (Goldsmith, 2000).

Return to Top

## **PUBLIC HEALTH PROFESSIONALS**

• Most public health institutions have been very slow in adopting and integrating information technology into their workflow because of inadequate training, lack of public health-oriented eHealth tools, and cost considerations.

The ten essential public health services revolve around three core public health functions, which include assessment of information on the health of the community, comprehensive public health policy development, and assurance that public health services are provided to the community (Public Health Functions Steering Committee, 1994). Online applications that support these public health functions are limited. Public health professionals are just beginning to use the Internet to facilitate disease control and surveillance initiatives (Klausner et al., 2000; CDC, 1999). Although uses such as email are commonly employed, most public health institutions have been very slow in adopting and integrating information technology into their workflow. Part of this problem stems from the fact that public health departments have been traditionally underfunded, and many personnel have not been adequately trained to use technology. In 1999, less than half of local health departments had continuous high-speed Internet access and almost 20 percent did not have email capacity (Bailey, 1999). Another major reason is the relative lack of public health-oriented eHealth tools available perhaps because developers generally do not perceive a large enough market for such tools.

Return to Top

## **EMPLOYERS AND PURCHASERS**

- Employers often sponsor eHealth tools for their employees as a way to help contain health care costs and to enhance employee health.
- Both private and public sector purchasers of health care products and services have a substantial impact on eHealth adoption by virtue of their purchasing and implementation decisions.

Employers, particularly large employers, are often sponsors of eHealth tools for their employees. Most of these sponsored products are online tools related to worksite health promotion and employee benefits selection. However, some large multinational corporations have invested in telehealth solutions to enhance their ability to provide higher quality care for their overseas employees.

There are essentially two major drivers that influence employer policies and decisions about implementing eHealth tools. The containment of health care costs, which often accounts for a substantial proportion of corporate expenses, is paramount, especially because health-related costs and insurance premiums have risen substantially in recent years for many employers (Arthur Andersen, 2000). The other major consideration is enhancing employee health and satisfaction, which may lead to greater productivity, less absenteeism, reduced staff turnover, and reduced workers' compensation claims. Thus, many eHealth companies, in areas such as self-care and health promotion and disease prevention, have identified large employers as their primary market for eHealth tools. This may continue as long as defined benefit plans outweigh defined contribution plans. If this axis shifts, consumers will be drawn to make more decisions.

Given the pressures employers face, eHealth tools intended for employer sponsorship will need to demonstrate either reduction in health care costs or enhancement in employee health or satisfaction. Some observers believe that if employers eventually adopt a defined contribution model for health-related benefits and allow greater flexibility and choice, a new class of innovative Internet-based health insurance companies will emerge (Healthcare Business, 2000). In a defined contribution model, providers will need to employ Internet technologies to market effectively to a much more diverse group of customers (employees versus employers). Emerging companies, such as Vivius (www.vivius.com), for example, help employers implement this model by facilitating provider-consumer marketplaces for pre-paid services and allowing employees to create a personalized health plan.

As mentioned previously, both private and public sector purchasers of health care

products and services have a substantial impact on eHealth adoption by virtue of their purchasing and implementation decisions. Influential purchasers include large employers, government programs (e.g., Medicare and Medicaid), and purchasing coalitions (e.g., Pacific Business Group on Health). Typically, purchasers seek higher quality and lower costs and many consider the Internet to be an important vehicle to achieve their goals by facilitating their transactions with health plans and other vendors.

Return to Top

<sup>7</sup> Search conducted May 16, 2001 using <u>search.yahoo.com/search?p=AIDS</u>.

<sup>8</sup> A federal appeals court ruled the Children's Online Protection Act as unconstitutional in June 2000 (U.S. Court of Appeals, 2000). This bill is considered to be a follow-up to the 1996 Communications Decency Act, which as unanimously struck down by the Supreme Court.

# OVERVIEW eHEALTH ISSUES

#### Table of Contents

**Foreword** 

**Preface** 

**Acknowledgements** 

#### **Executive Summary**

**Introduction** 

Current Status of the eHealth Sector

Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

QualityPrivacy, Confidentiality, and SecurityAccess and the Digital DivideContent and Application DevelopmentResearch and EvaluationData Standards DevelopmentIntegration of eHealth Segments

QUALITY

• Proposed approaches to ensuring quality of eHealth resources include accreditation, certification, rating systems, public disclosure of key information about a site or product, and posting of seals and logos indicating compliance with a set of quality standards.

As in the "offline" health care industry, quality assurance and improvement are major issues for the eHealth sector. The barriers to creating and hosting a health Web site are minimal, allowing developers with varying degrees of scientific expertise and training to develop Web sites and tools. Many studies have documented that a substantial proportion of online health resources are incomplete or inaccurate (Li et al., 2001; Stone et al., 2001; Suarez-Almazor et al., 2001). Evaluations of 25 health Web sites and 14 search engines available in English and Spanish during the second half of 2000 found that search engines were not efficient in locating relevant content and that coverage of key clinical information in the topics studied was poor and inconsistent (although accuracy was generally good) (Berland et al., 2001). In addition, the average reading level was collegiate for the English Web sites and 10th grade for the Spanish Web sites. The inconsistent quality of sites and, in some cases, intentionally deceptive online practices have raised strong concerns among consumers and policymakers about ensuring the quality of online resources (Robinson et al., 1998; SPICH, 1999). Consequences of poor quality eHealth applications include inappropriate treatment or delays in seeking appropriate health care, damage to the patient-provider relationship, and violations of privacy and confidentiality.

Several approaches to eHealth quality assurance have been proposed. One approach to quality assurance is to designate an independent entity, such as American Accreditation Healthcare Commission (URAC) (www.urac.org/websiteaccreditation.htm), to accredit developers by evaluating their ability and capacity to consistently produce high-quality and effective products. Analogous accreditation organizations for managed care organizations and health care facilities are The National Committee for Quality Assurance and The Joint Commission on Accreditation of Healthcare Organizations. In addition, various groups have promoted certification, a process where specific applications are evaluated for quality, safety, and effectiveness. An example of an organization that has adopted a similar approach for consumer products is the Underwriters Laboratory. Although the notion of accreditation and certification may have some merit, several technical and policy issues will need to be addressed for them to be successful (SPICH, 1999). Perhaps the most formidable issue is the development of consensus criteria and a valid implementation model for eHealth accreditation and certification. Also, the question of which independent organization could conduct an objective assessment of developers and applications would need to be addressed. On a practical level, the sheer number of eHealth sites and developers may make these approaches extremely difficult to implement.

Another approach to quality improvement is to provide results of rating systems or other evaluation mechanisms to help users in selecting online resources. Many examples of such rating tools are currently in use (Kim et al., 1999). Several companies also provide reviews by "experts" or allow users to post their own site reviews (e.g., <u>www.gomez.com</u>). This approach is similar to the *Consumer Reports* model. In addition, some companies and organizations conduct periodic assessments of eHealth sites and provide awards in different categories (e.g., eHealthcareworld, Global Information Infrastructure Awards, Partnerships for Networked Consumer Health Information Technology Games, Webby Awards, World Wide Web Health Awards). One shortcoming of this approach is that the criteria used by one entity to evaluate a site may differ substantially from those used by others. Individual users may even rely on different assessment criteria, depending on the context in which the person is using the resource.

Because of the above-mentioned shortcomings in the accreditation, certification, and rating system models, public disclosure of key information about a site or product (e.g., disclosing identity of the developer and sponsor, purpose and sources of content, privacy protections, advertising, evaluation results) has been proposed as a viable alternative (SPICH, 1999). An "evaluation reporting template" and a "disclosure statement" are available as implementation models for this approach, which is similar to the labeling requirements for certain consumer products.

Posting of seals and logos associated with a set of explicit standards is an increasingly popular approach. The most commonly used seal for eHealth sites is the Health on the Net (HON) code seal, which can be displayed if a developer reports compliance with a set of ethical principals (HON Foundation, 1997). In

May 2000, two other groups proposed voluntary ethical standards for eHealth companies and other developers, which have been endorsed by many commercial companies and organizations (Hi-Ethics, 2000; Internet Healthcare Coalition, 2000). In October 2000, the Hi-Ethics, HON Foundation, and the Internet Healthcare Coalition announced the formation of a coordinating committee to collaborate on a common glossary to facilitate user understanding of otherwise disconnected ethical conduct codes. TRUSTe, an organization well known for their privacy seals, recently announced the development of a quality seal for eHealth sites based on the Hi-Ethics guidelines (TRUSTe, 2000). An international system of ratings, self-labeling, and "quality seals" for health Web sites has also been proposed (Eysenbach et al., 2000). In addition to the above organizations, the American Medical Association recently released their quality guidelines for health Web sites (Winker et al., 2000). Although a number of major eHealth companies have pledged compliance with the proposed standards, and the specificity of the standards surpasses those previously available, it is unclear how adherence to these standards will be independently audited and enforced.

Regardless of the approach to voluntary quality assurance and improvement accreditation, self-regulation, rating systems, disclosure, seals and logos— it will need to be evaluated for effectiveness in promoting quality or changing developers' and consumer behavior. In addition, given the competing proposed approaches, further consensus building or unification of approaches may create less confusion among the public. Because current quality assurance strategies were developed for relatively static health interventions, further efforts are needed to explore new models that address the dynamic nature of eHealth technologies.

As mentioned previously, eHealth technologies are only beginning to be deployed in the area of health care quality improvement (Bates and Gawande, 2000). The Internet offers a cost-effective platform for collecting and disseminating quality of care data. Online tools that facilitate quality assurance and measurement are currently limited, but several companies and organizations have developed interesting applications in this space (e.g., www.healthgrades.com, www.healthscope.org). A Pacific Business Group on Health initiative (www.healthscope.org) provides public access to various process and outcome measures that must be reported to the employer purchasing coalition by its contracting health plans. Another potential area in which eHealth technologies can have an impact is quality assurance and monitoring of services. For example, in the case of online-facilitated prescriptions, it is possible to monitor the time that it takes for an order to be filled, the potential for adverse interactions with other medications, whether appropriate prescribing information has been provided to the patient, and the response time for related provider-patient online messages. Additional eHealth research and application development in the health care quality arena are needed.

## PRIVACY, CONFIDENTIALITY, AND SECURITY

- Americans are acutely concerned about privacy related to online health information. Until the public is confident that online health information will not be shared or sold without their consent, and that databases are secure, many types of eHealth tools will not be widely adopted.
- A recent analysis of the privacy policies and practices of popular eHealth sites found that most did not meet minimum fair information practices.
- In considering online privacy protections, users' desire for privacy needs to be balanced with their desire for a personalized Web experience.
- The extent to which the HIPA A regulations will affect eHealth companies will depend on the nature of their operations. However, it likely will not cover many eHealth companies that are not directly involved in health care provision, insurance, and health care clearinghouse services, but otherwise do collect personal health information.

In the last few years, several widely publicized breaches of network security and global viruses have elevated the issue of online data and computer security to the center of the public eye. These episodes included unauthorized access to personal user information and the stealing and posting of files containing personal identifiers and credit card numbers from supposedly secure Web sites. Perhaps the most widely publicized episodes in recent years were the hacking and denial of service attacks against several of the largest online companies. In addition, the recent "Love Bug" email virus, which damaged PCs, clearly demonstrated how rapidly viruses spread worldwide over the Internet (Government Accounting Office, 2000). In 2000, about 4,700 electronic patient files containing treatment information were stolen from the University of Washington' computer network by a hacker who apparently wanted to expose lax security (Seattle Times, 2000). Although the overwhelming majority of reported security breeches do not directly involve healthrelated data, they foster the perception that online data of any kind are susceptible to security threats. Privacy lapses, however, don't necessarily result only from intentional intrusions. For example, a health plan technician, in the process of upgrading software, accidentally sent 19 members 858 email messages, some of which contained sensitive information intended for others (Brubaker, 2000).

Americans are especially concerned about privacy related to online health information. A recent Gallup poll showed that about half of Internet users have serious privacy and security fears (Gallup, 2000). According to one survey, 75 percent of those seeking health information on the Internet are "concerned" or "very concerned" about sites where they have registered sharing their personal health information with a third party without permission (California HealthCare Foundation and the Internet Healthcare Coalition, 2000). Another survey showed that only 7 percent of respondents were very willing to store or transmit personal health information on the Internet (MedicAlert Foundation, 2000). Among the 37 million online users who do not currently use online health information, about 6.3 million (17 percent) are not doing so primarily because of privacy and security concerns (Cyber Dialogue, 2000). They fear that insurers could use personal health data to limit insurance coverage or that employers could use this data to limit job opportunities. Until the public is confident that health information will not be shared or sold without their consent, and that databases are secure and cannot be "hacked," many types of eHealth tools, such as electronic health records, will not be widely adopted. The public perception that electronic-based records are more susceptible to privacy violations is widespread even though such records have several advantages (e.g., automatic audit trails, selective release of information) over paper-based records (National Research Council, 1997). Initiatives are underway to improve the security of health information exchange over the Internet using public key cryptography, certificates, and other technologies (e.g., www.healthkey.org).

Some consumers' fears about online privacy seem to be well founded. A recent analysis of the privacy policies and practices of 21 popular eHealth sites found that most did not meet minimum fair information practices, such as providing adequate notice and giving users control over their information (Goldman et al., 2000). Through the use of banner ads, profiling, and cookies, many sites were collecting information often without the users' knowledge or consent. In addition, there were many inconsistencies between posted privacy policies and actual practice. These results spurred industry efforts to establish voluntary ethical standards for health Web sites as discussed previously.

Cookies are used to keep track of a user or a specific transaction by placing a small bit of information on the user' computer. By doing so, sites can locally store user information and offer a more tailored experience and also eliminate repetitive chores like keying in of personal information for regular transactions. Several online advertising companies, however, use cookies to track the movements of users across different Web sites and develop online profiles of users without their knowledge or permission. Banner ad-tracking companies, such as Doubleclick, have been a focus of intense public criticism because users of sites with enabled banner ads were never notified that their activities were being tracked across sites. Recent developments are "Web bugs," which are small programs represented on a Web page by a one-pixel-by-one-pixel dot— the smallest possible point on a monitor. These invisible bugs send information back to the site or a third party but are impossible to detect unless the page's source code is examined. One case involved a company that used a "Web bug" to place hidden code to track the activity of users of Web pages maintained by 11 pharmaceutical companies (O'Harrow, 2000).

As a result of public pressure, the Network Advertising Initiative, which represents

90 percent of network advertising companies, proposed a set of self-regulatory guidelines for their industry. In July 2000, the Federal Trade Commission issued a report that supported the Initiative's guidelines and also called for legislation to ensure those companies not represented by the Initiative would also abide by the guidelines (FTC, 2000). Under the proposed principles, consumers will: (1) receive notice of network advertisers' profiling activities on host Web sites and be able to opt-out of profiling; (2) be given reasonable access to personally identifiable information stored by a network advertiser for profiling purposes; (3) have a choice to opt-in before previously collected non-personally identifiable data is linked to personally identifiable data; and (4) receive "robust" notice and an opt-out choice for prospective uses of personally identifiable information. However, voluntary standards are by definition optional and Web site sponsors can choose to ignore them. Many observers view the Network Advertising Initiative as the industry' attempt to ward off federal legislation on online privacy. With respect to online privacy, Congress recently passed the Children's Online Privacy Protection Act9, which requires verified parental consent before personal information from children under 13 can be collected or disseminated online.

Other examples of industry self-regulation efforts are "seal" programs for privacy and quality (e.g., TRUSTe [www.truste.com], BBBOnline [www.bbbonline.com], Secure Assure [www.secureassure.com]). Perhaps the most visible of these is the TRUSTe seal, which is licensed to sites that adhere to established privacy principles and agree to comply with ongoing oversight and consumer resolution procedures. However, TRUSTe itself has been criticized for its enforcement procedures and potential conflicts of interest (Rafter, 2000).

As a result of the Health Insurance Portability and Accountability Act (HIPAA) of 1996, the U.S. Department of Health and Human Resources issued final rules in December 2000 requiring the health care industry to ensure the security and protect the privacy of medical records and personal health information by 2003 (U.S. Department of Health and Human Services, 2000a). Under HIPAA, health plans, health care clearinghouses, and health care providers who conduct certain financial and administrative transactions (e.g., electronic billing and funds transfers) electronically are required to implement privacy and security protections within two years. The rules pertain to all medical records and other individually identifiable health information held or disclosed by a covered entity in any formelectronic, paper, or conversation. Because the rules are limited to those "covered entities" described above, it also mandates that these covered entities develop contracts with business associates to protect any personal health data it receives from the covered entity. The mainstay of the HIPAA regulations requires providers and health plans to disclose how they can use, store, and share health information; ensure patient access to their medical records; and obtain patient consent before releasing patient information. With some exceptions, personal health information can be used for health purposes only. The allowance for providers and payors to use medical information for marketing purposes, without affirmative patient consent or the opportunity to opt-out in advance, has been criticized (Gellman,

2001). The extent to which the HIPAA regulations will affect eHealth companies will depend on the nature of their operations. However, because the regulations are focused on health care providers, health plans, and health care clearinghouses, it will likely not cover many eHealth companies that are not directly involved in those sectors, but otherwise do collect personal health information (Goldman and Hudson, 2000). For example, HIPAA does not address the growing trend towards personalization in Web sites and online advertising, which may result in more personal data being collected and potentially used for purposes not intended by the user and without their knowledge or permission.

With the advent of Internet access at the workplace, an employee's right to privacy and an employer's prerogative to monitor and ensure the appropriate use of company resources in the workplace also needs to be balanced. In 1999, 27 percent of major U.S. firms monitored employee email messages (American Management Association, 2000), and about 17 percent of Fortune 1000 companies and half a dozen federal agencies used software to monitor the use of office PCs by employees (Shiver, 1999). By 2001, about 80 percent of large companies are expected to be using such software. Employer monitoring of Internet use may prevent or limit the use of sensitive online health resources at the workplace, which may be the only type of Internet access available for some individuals.

In considering online privacy protections, users' desire for privacy needs to be balanced with the desire of consumers and health professionals for a personalized Web experience (FTC, 2000). Unfortunately, there is a lack of research on ways to match the privacy needs of users with their expectations of eHealth technologies.

Return to Top

## ACCESS AND THE DIGITAL DIVIDE

- There is a gap in computer and Internet access among certain population groups when segmented by income, educational level, race/ethnicity, age, disability, or other parameters.
- Infrastructure access, the focus of many access initiatives, is only one dimension of the digital divide, of which health and technology literacy and appropriate content are also key elements.
- Lower socioeconomic groups are increasingly gaining Internet access, but it is likely that the digital divide will persist albeit with an evolving focus as new technologies become available.

The term "digital divide" is most often used to refer to the gap in computer and Internet access among population groups segmented by income, educational level, race/ethnicity, age, disability, or other parameters. For example, in August 2000, households with incomes of \$75,000 or higher were more than six times as likely to have Internet access than households with incomes less than \$15,000 (National Telecommunications and Information Administration, 2000). African American and Hispanic households were approximately one-half as likely to have Internet access at home as Asian/Pacific Islander and white households. In addition, disabled persons are only half as likely to have Internet access as those without a disability. The contribution of various socioeconomic factors to the digital divide is controversial, but more recent studies suggest that the divide may be largely associated with economic, educational, and age-related differences, rather than with racial or ethnic groups (Nie and Ebring, 2000; National Public Radio, 2000).

Recent data suggests that the digital divide may be closing in some aspects (National Telecommunications and Information Administration, 2000). Although lower-income families account for a small proportion of all Web users (Figure 2), they represent the fastest growing segment of recent users and computer purchasers (National Public Radio, 2000). For example, users with annual household income of less than \$25,000 accounted for less than 10 percent of the total user population in June 2000, but this segment of users grew 49 percent in one year compared to a 23 percent growth among all users (Rickert, 2000).

FIGURE 2 Proportion of Internet users by annual household income versus proportion of income levels in the general population as of June 2000.



*Note:* Income group levels were adjusted for clarification purposes from those originally presented.

*Source:* Rickert A. The Dollar Divide: Demographic Segmentation and Web Usage Patterns by Household Income. New York: Media Metrix. August 21, 2000. Available at: <a href="https://www.mediametrix.com/data/MMXI-USHHI-0600.pdf">www.mediametrix.com/data/MMXI-USHHI-0600.pdf</a>.

Current efforts on the digital divide have largely focused on providing access to PCs and the Internet and hardware and software training. Government agencies or foundations have funded most access-oriented programs but corporate efforts in this area are increasing. Examples of access initiatives include the Universal Service Fund (E-Rate), the Community Technology Centers program of the Department of Education, and the Department of Commerce's Technology Opportunities Program. One of the most popular access enhancement models is the establishment of community computer/Internet centers in lower income neighborhoods, which have been supported by various foundations, corporations, local businesses, and government agencies. For example, the U.S. Department of Housing and Urban Development's Neighborhood Networks program promotes multi-sponsor funding of computer learning centers in privately owned HUD-assisted and/or -insured housing (U.S. Department of Housing and Urban Development, 2000).

Infrastructure access, the focus of many access initiatives, however, is only one dimension of the digital divide, of which technology, health literacy, and appropriate content are also key elements (Eng et al., 1998). Most access initiatives typically do not include instruction on how to use and evaluate online resources, which becomes increasingly important with the proliferation of Web sites and online marketing efforts. Certain populations also have difficulty accessing or utilizing online health resources because the content or the medium is inappropriate for them. This may be due to inadequate technology, health, or reading literacy skills; a disability; or inability to communicate in English. In addition, most health Web sites are primarily text-based and are primarily designed for educated audiences even though about half of the U.S. population has rudimentary or limited reading skills (National Work Group on Literacy and Health, 1998). For example, an analysis of medical information on Web sites showed that, on average, materials were written at a 10th grade reading level, which is not comprehensible to the majority of people (Graber et al., 1999). A limited analysis of Web content in several areas including health found a discrepancy between what underserved families wanted online and what was available (Lazarus and Mora, 2000). Gaps were identified in the following areas: practical information focusing on local communities, content written at a basic literacy level, content for non-English speakers, and culturally diverse information, especially in health. The inability to communicate in English is a major barrier in accessing health services, but non-English online health resources are limited. The impact of technical skills, literacy, sociocultural factors, disability, language, and other potential barriers to utilization of eHealth resources requires additional study.

The concept of universal access to the Internet— defined broadly as the ability to access, comprehend, and utilize information and support appropriate to one's personal characteristics— as a critical tool for health improvement, is gaining support in the larger context of the digital divide (Eng et al., 1998). Consistent with this concept, several of the national health objectives (Healthy People, 2010), which were developed by a coalition of federal and nonfederal organizations, seek to expand access to the Internet at home, improve health literacy, and improve the quality of online health resources (U.S. Department of Health and Human Services, 2000b).

Despite current data showing that lower socioeconomic groups are increasingly gaining Internet access, it is likely that the digital divide will persist albeit with an evolving focus as new technologies become available. There will be a persistent gap in access to new technologies— at least by household income, educational level, and perhaps geographic location— because they will always be relatively expensive and less available in certain areas as they are initially deployed.

As enhanced multimedia services and capabilities become integrated into Internetbased tools, broadband access may become as important for accessing future health care and other services as narrowband access is today for obtaining health information. Thus, the next focus of the digital divide issue will likely center around access to broadband Internet service (Federal Communications Commission, 2000). The two most commonly available broadband technologies are DSL (deployed over regular copper telephone lines) and cable modem (deployed over coaxial cable TV lines). For economic and other reasons, DSL is being deployed primarily in urban areas and cable modem service is being deployed mostly in large cities, suburban areas, and towns. DSL is available in more than 56 percent of cities with populations greater than 100,000, but less than 5 percent of towns with populations less than 10,000 people (National Telecommunications and Information Administration, Rural Utilities Service, 2000). Similarly, cable modem service is available in more than 65 percent of cities with populations greater than 250,000, but less than 5 percent of towns with populations of 10,000 or fewer have such service.

Some jurisdictions have already invested in a broadband infrastructure primarily for economic improvement. The city of LaGrange, GA, for example, has financed and constructed a fiber-coaxial broadband network and is providing free cable modem service to all residents as a public good, and was named "Intelligent City of the Year" (Delio, 2000). But, as other like-minded cities and towns are learning, providing infrastructure access is not sufficient if technology skills are lacking (Associated Press, 2000).

The issue of the digital divide has recently received strong attention from political leaders. In April 2000, President Clinton obtained commitments from more than 400 companies and nonprofit organizations to his "National Call to Action" to tackle the digital divide in the United States (The White House, 2000). In the global arena, the digital divide cause has reached the heads of state of the G8 countries, who have adopted an information technology charter to help developing nations access and use the Internet to improve economic opportunities (World Economic Forum, undated). The G8 countries have created a Digital Opportunity Taskforce, which will report back to the 2002 G8 Summit.

#### Return to Top

## CONTENT AND APPLICATION DEVELOPMENT

- Considerable overlap and gaps exist in eHealth content.
- Although new business models that support development for small markets are evolving, it is likely that targeted efforts are needed to address the gaps in eHealth development.
- Many developers have limited expertise or experience in technical or topic-

specific areas that are critical for product development and evaluation.

A variety of disparate individuals and entities are involved in eHealth development, and, as a result, development efforts are typically uncoordinated and essentially independent— even within the public sector. Not surprisingly, there is considerable overlap and gaps in eHealth content. Duplication of effort is evident when examining online resources in areas related to major health problems. Table 3 shows that, at a minimum, hundreds to thousands of unique Web sites are available under the same condition/disease keywords. In addition, dozens of vendors and organizations produce similar eHealth tools, such as risk assessment tools, electronic health records, and clinical information systems, many of which are not interoperable. Although some overlap of effort may be desirable to engender constructive competition, it is also an inefficient use of development resources. It is possible that this may be a self-correcting problem, in that those who create online products that do not add value to existing offerings will not be able to attract or retain a sufficient user base to sustain them.

# **TABLE 3** Number of unique Web sites indexed by Yahoo! by specific keywords.

CONDITION/DISEASE	NUMBER OF SITES
Cancer	1747
AIDS	1656
Pain	790
Smoking	693
Weight loss	470
Pregnancy	441
Diabetes	329
Breast cancer	316
Heart disease	277
Breastfeed(ing)	195
Arthritis	197
Viagra	144

*Note:* The above numbers are English language sites found using a single search term on Yahoo! on March 16, 2001. Although a small percentage of the above sites may not be relevant in that category and some specialize in different aspects of the subject area, Yahoo! and Web search engines only provide access to a fraction of all Web sites. In addition, the number of sites listed does not include searches with related terms (e.g., smoking: tobacco, nicotine, and cigarettes). Therefore, duplicative efforts may be even larger than suggested here.

Current market forces are driving rapid eHealth development in some areas, such as clinical care support, health care transactions, and business-to-business

commerce. Although new business models that support development for small markets are evolving, market demand and investors are unlikely to spur development efforts in certain neglected areas. It is likely that targeted efforts will be needed to address the gaps in eHealth development. eHealth topics and populations that have not been adequately addressed by commercial endeavors include population health-oriented tools, applications that integrate various health sectors (e.g., clinical care and public health), tools for "orphan" or rare health conditions, and applications relevant to underserved populations (e.g., low-income, non-English speaking, certain racial/ethnic groups). In addition, most of the online content available is still created and organized in paradigms borrowed from the print industry. Scalable models of information architecture optimized for online health care decision-making are needed.

Most eHealth sites and tools do not offer population health-related functions, such as population-based registries and community health tools, perhaps reflecting the perception that implementing such functionality may not translate into substantial revenue. This perception may be rooted in the fact that spending for population-based services accounts for only about one percent of total health care expenditures in the United States (CDC, 1997).

Many eHealth tools support users in making health decisions or implementing some type of behavior change (Noell et al., 1999). Although no unified psychosocial theory or model exists to guide eHealth development in such areas, established social science theories, models, and evidence are sometimes employed as the basis for eHealth tools development (SPICH, 1999). The extent to which eHealth developers employ evidence-based concepts and processes is unclear and varies depending on the expertise and resources of the developer. Those who do not possess such expertise or resources may instead elect to marry "snazzy" or cuttingedge technologies with inappropriate content or design methods to attract users.

Many developers have limited expertise or experience in technical or topic-specific areas that are critical for product development and evaluation. Increased information exchange and collaboration among developers and between developers and other stakeholders (e.g., developers and users, designers, and evaluators) may result in more efficient uses of special expertise and development resources, and improve the quality and effectiveness of resulting applications. The challenge is to foster collaborative eHealth development in the context of market competition and the desire to safeguard proprietary approaches. For example, in the current environment, technologists with minimal health expertise may develop glitzy applications that are not rooted in evidencebase approaches, health educators who aren't technically savvy may develop good decision support tools that can't support multiple simultaneous users, and physicians may develop medically accurate Web sites that consumers can't understand. Integrating different types of expertise in development teams would likely result in more effective applications.

#### Return to Top

## **RESEARCH AND EVALUATION**

- Most assessments of eHealth interventions have been limited to small groups that may not be representative of the parent population, have not been randomized control trials, had limited follow-up periods, or only assessed proprietary interventions that may or may not be replicable.
- There are big gaps in basic and applied research related to eHealth, including the health and social impact of eHealth tools on the population level.
- Dynamic developments in technology complicate efforts to extrapolate findings from specific evaluations to future applications.

eHealth interventions have been shown to enhance social support and cognitive functioning (Winzelberg et al., 2000; Gustafson, Hawkins et al., 1999; Tate et al., 2001); enhance learning efficiency (Bell et al., 2000); improve clinical decision-making and practice (Dayton et al., 2000; McMullin et al., 1999); reduce health services utilization (Gustafson, Hawkins et al., 1999; Health Hero Network, Inc., 2000), and lower health care costs (Gustafson, Hawkins et al., 1999; Stoloff et al., 1998) among certain study groups. Most of these studies, however, were limited to small groups that may not be representative of the parent population, were not randomized control trials, had limited follow-up periods, or only assessed proprietary interventions that may or may not be replicable. A recent literature review of eHealth applications in the area of behavior change found that most studies were descriptive and few were rigorous studies (Pro-Change Behavior Systems, 2001). No studies have examined the cost-effectiveness of eHealth tools in large populations compared to similar interventions using traditional media.

eHealth developers do not routinely conduct evaluations, especially post-market assessment for effectiveness (SPICH, 1999). In addition, when commercial companies and other private sector organizations do conduct evaluations, the results are often not publicly available. Only a small number of randomized controlled studies have examined the effectiveness of eHealth tools in improving health status or the outcomes of health care (Agency for Healthcare Research and Quality, 1997; SPICH, 1999).

A comprehensive research and demonstration project agenda for eHealth does not exist. However, the Science Panel on Interactive Communication and Health, a consensus expert panel, has identified several gaps in research and demonstration projects for several eHealth areas (SPICH, 1999). Gaps in basic and applied research include: impact of eHealth on behavior change and health outcomes; population and user-specific differences in use of online health resources; measurement approaches and tools for assessing eHealth efficacy and effectiveness; relative effectiveness of Internet versus non-Internetbased tools; characteristics of effective eHealth tool design; and implementation models for eHealth use and integration among professional groups and institutions. Examples of appropriate demonstration projects include: eHealth interventions for population health issues; integration of eHealth tools in home, clinical, worksite, and other settings; projects that integrate clinical care and public health; models that expand public access to online health resources; and initiatives focused on low-income and minority populations.

In addition, there are no studies of the health and social impact of eHealth tools on the population level. Areas for additional research include the impact of eHealth on total burden of illness, health services utilization, health care costs, employer costs, the clinician-patient relationship, and health care and public health systems. The potential differential impact of eHealth tools on specific subpopulations is also unknown. In addition, it would be useful to monitor and evaluate the impact of eHealth– and Internet-related policies including those related to quality improvement, privacy and data security, technology access, and reimbursement and liability for Internet-based services.

The Internet has greatly facilitated survey research. Several online survey research companies have emerged in recent years that typically conduct customized research using their private online panels (e.g., <u>www.greenfieldonline.com</u>, <u>www.harrisinteractive.com</u>, <u>www.npdor.com</u>). Panel members are typically selected for a particular study and are paid a fee or entered into a drawing for cash or prizes for completing an online survey or focus group. Major advantages of these online panels compared to traditional phone, mail, and person-to-person surveys include increased speed and reduced costs of implementation. However, the representativeness of these panels to the general population and the validity of online responses need to be seriously considered.

Return to Top

## DATA STANDARDS DEVELOPMENT

- Outside of the approximately 3 billion health care claims processed annually, an estimated additional 25 to 30 billion clinical, financial, and administrative health care transactions take place, with only a small fraction of these transactions transmitted electronically.
- Under the Health Insurance Portability and Accountability Act (HIPAA) of

1996, standards for data content and formats for submitting electronic claims and other administrative transactions were established.

Many observers believe that a vision of convergent— or at least interoperable clinical, laboratory, and public health information systems appropriately linked to personal health information, will provide unprecedented opportunities for improving individual and population health services and knowledge (National Committee on Vital and Health Statistics, 2000a). However, most current data systems are proprietary legacy systems running on many different operating systems and platforms, and were conceived by dozens of different vendors. To enable universal data exchange capability, translating software is often required and data exchange standards will need to be developed.

Large health care organizations, such as hospitals and pharmacies, process more than 85 percent of claims electronically through EDI (Electronic Data Interchange) systems, but physician offices have lagged behind in terms of electronically processed claims (Wit Capital, 2000). Outside of the approximately 3 billion health care claims processed annually, an estimated additional 25 to 30 billion clinical, financial, and administrative health care transactions take place, with only a small fraction of these transactions transmitted electronically.

In August 2000, the U.S. Department of Health and Human Services released its final rule for electronic transactions in response to a congressional mandate to simplify administrative transactions under HIPAA. The rules establish standard data content and formats for submitting electronic claims and other administrative transactions, thus enabling providers to bill for and receive payment for services and determine eligibility for insurance coverage (U.S. Department of Health and Human Services, 2000c). Because the health care industry in the United States uses some 400 different formats for health care claims alone, it is estimated that the industry could save nearly \$30 billion over a decade. The health care industry has until October 2002 to implement these new national standards.

The National Committee on Vital and Health Statistics recently issued a report to promote the development and adoption of uniform data standards for patient medical record information. The Committee found that the major impediments to electronic exchange of such information are limited interoperability of health information systems, limited comparability of data exchanged among providers, and the need for better quality, accountability, and integrity of data (National Committee on Vital and Health Statistics, 2000b).

Open standards for organizing consumer-oriented health terms and mapping them to standard medical terminology systems (e.g., SnoMedRT) are lacking. Such standards would allow consumers to access online medical information, including their personal health record, without having to know complicated medical terminology schemes. Without a set of standards to simplify and enhance consumers' ability to retrieve useful health information, information from multiple sources may be coded completely differently or may go completely uncoded. Currently, such terminology systems are only being developed in isolation from one another, and in proprietary formats.

Return to Top

## **INTEGRATION OF eHEALTH SEGMENTS**

- There is a need to integrate the various features and functions of eHealth tools, including health information and support, transaction processing, electronic health records, clinical and public health information systems, compliance and disease management programs, distance learning, and behavior change and health promotion.
- Linkages are needed between clinical and public health information systems and personal health information that is increasingly being held by individuals.
- Many longstanding political, economic, structural, and competitive barriers to collaboration and integration will need to be overcome to integrate the various eHealth-related sectors.

There are tremendous parallels between the online and "offline" worlds with regard to the segmentation of health-related sectors. That is, the lack of integration and communication among the fields of health care, public health, and personal health also carry over into the online world.

There is a need to integrate the various features and functions of eHealth tools, including health information and support, transaction processing (e.g., scheduling appointments, ordering prescriptions), electronic health records, clinical and public health information systems, compliance and disease management programs, and behavior change and health promotion. In addition to potentially improving operational efficiencies in delivering health care and public health services, such eHealth integration promises to augment the ability of professionals to provide a seamless continuum of care.

Much of the existing fragmentation in implementing such tools may reflect the fact that most eHealth companies offer relatively narrow focused products. However, there is some integration or, at least, linkages between health care applications and personal health tools. Examples of this trend include commercial versions of the online personal electronic health record, which allow clinicians, patients, and consumers to input and access health and medical data through the Web. In addition, many large eHealth companies segment their user interfaces and content to serve multiple audiences, including providers and consumers (e.g., <u>www.medem.com</u>, <u>www.medscape.com</u>, <u>www.webmd.com</u>). True collaborative activities among health care providers and patients, however, such as online-shared decision-making, are only in the early developmental or implementation stages (e.g., <u>www.healthdialog.com</u>).

Although the Internet offers an unprecedented opportunity to integrate various health related sectors, many longstanding political, economic, structural, and competitive barriers to collaboration and integration must still be overcome. For example, the CDC is in the process of electronically integrating some 73 separate disease surveillance systems that were developed by separate internal groups through the years (CDC, undated). Among the federal health agencies, the reliance on categorical funding streams presents formidable challenges to the integration of federal health care and public health information systems. And, with regard to information systems sponsored by public and private organizations, the lack of common data definitions and structure standards may make integration efforts unrewarding even if the political will for integration existed. If these barriers can be addressed, there is great potential that information systems integration (or, in certain cases, more appropriately compatibility) on a large scale (e.g., linking health care, public health, environmental, and socioeconomic information systems) may result in unprecedented opportunities for health research, provided that appropriate privacy concerns are addressed. The results of such research could lead to dramatic improvements in health status, health care quality, and reduced health care costs.

Return to Top

<sup>&</sup>lt;sup>9</sup> To be distinguished from the Children's Online Protection Act.

# A CAUTIONARY VIEW OF eHEALTH

#### **Table of Contents**

Foreword

**Preface** 

**Acknowledgements** 

**Executive Summary** 

**Introduction** 

## Current Status of the eHealth Sector

Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

Fraudulent Activities and Poor Quality ResourcesViolations of Privacy and ConfidentialityUnintended ErrorsPotential MisuseSocial IsolationWidening the Socioeconomic Divide

• Major risks associated with the widespread use and adoption of eHealth tools include fraudulent online activities and poor quality resources, violations of privacy and confidentiality, unintended errors from inadequately tested or complex tools, potential misuse of applications, increasing social isolation due to online activities, and widening the socioeconomic divide.

Although the promise of applying emerging information and communication technologies to improve health and health care is substantial, it is critical that enthusiasm for this prospect be tempered with an understanding of what technology can and cannot do. For example, although eHealth tools can enable providers 24x7 access to childhood immunization data, such tools cannot actually immunize children. Although eHealth tools can help individuals assess their health risks and guide them to consider specific actions they can take to avoid disease, they cannot ensure that the user will choose a healthier lifestyle. And, despite the fact that eHealth tools can facilitate population health interventions, they cannot guarantee that people in communities will adopt behaviors that improve their health. Some observers contend that the Internet has been over-promoted as the solution for the inefficiencies, redundancies, and quality deficiencies in the U.S. health care system, given that these problems are actually rooted in economic, organizational, legal, regulatory, and cultural conflicts (Kleinke, 2000).

Can technology lead to decrements in health and health care? Renowned technologists like Bill Joy of Sun Microsystems have highlighted the dangers of allowing advanced technologies unfettered reign in human systems (Joy, 2000). Although many have expressed doubt about some of the futuristic scenarios painted by Joy, most observers agree that there are some real concerns about the potentially harmful impact of emerging technologies.
Publicly documented cases of physical harm resulting from inappropriate use of eHealth resources are relatively rare (Black and Hussain, 2000; Weisbord et al., 1997). However, poor quality resources are endemic on the Internet, and most eHealth sites and tools have not been evaluated for effectiveness or impact (Robinson et al., 1998; SPICH, 1999). In assessing the potential opportunities for enhancing health, the following major risks associated with the use and adoption of eHealth tools should also be considered.

Return to Top

# FRAUDULENT ACTIVITIES AND POOR QUALITY RESOURCES

Given the low barriers to developing and hosting a Web site, a growing variety of entities and individuals- many of whom lack scientific expertise and trainingare developing and sponsoring sites that may result in unintentional harm. Even more worrisome are the numbers of Web sites that make deceptive and unsubstantiated health claims or perpetuate fraudulent and illegal activities (FTC, 1999; Siwolop, 2001), including the sale of controlled drugs (International Narcotics Control Board, 2001). Because the Internet allows for cost-effective marketing and rapid dissemination of fraud, it may become the medium of choice for such activities. Harmful effects from using inappropriate or poor quality tools include inappropriate treatment or delays in appropriate care especially among those with a serious illness, and wasted resources associated with pursuing ineffective treatments or care. In addition, the patient-provider relationship may be jeopardized when patients rely on poor quality information. The potential for harm is greatly augmented when users have difficulty in evaluating the quality or relevance of online health resources. Many of these concerns also apply to more traditional media, such as print, radio, and television. However, Internet-based interventions may deserve special consideration of their potential for harm because of how widely and rapidly they are disseminated and the power of interactive media to influence behavior and decision-making.

# VIOLATIONS OF PRIVACY AND CONFIDENTIALITY

To decrease administrative costs and improve efficiencies of care, some health organizations and eHealth companies are attempting to create seamless data networks among providers, laboratories, insurers, employers, and ultimately, consumers. The standards for data content and formats for electronic transactions promulgated under HIPA A will help catalyze this evolution. Such networks, however, may open up additional opportunities for inappropriate breaches of privacy, either from external intrusions or, more likely, from internal security lapses. This potential will be augmented when the electronic health record becomes widely adopted. The vision of integrated clinical and public health information systems can only be achieved if data security, privacy, and confidentiality are assured.

Return to Top

# **UNINTENDED ERRORS**

Increasingly sophisticated eHealth software, such as expert systems and decision support programs, employ complex algorithms that are usually transparent to the user. Without extensive testing and quality control in their design, such tools may generate erroneous results or unintended recommendations. Another possibility is that different components of complex eHealth tools, which are often authored by different developers, may interact in unexpected ways. In addition, some tools use Internet software "agents" that automatically update information without human interference or validation. In some cases of poorly-engineered products, unintended errors may result with unforeseen circumstances (SPICH, 1999).

Return to Top

## **POTENTIAL MISUSE**

The recent explosion in the variety of health services that are being offered online, including both physical and mental health services, will likely continue in the

foreseeable future as a mechanism to reduce costs of care delivery and to improve access to services. Because of the potential for substantial cost-savings associated with providing services online, insurers, payors, and employers, may be anxious to substitute online services for some face-to-face services in the future. However, the ultimate impact of this transition on health care quality and outcomes is unknown because research on the relative effectiveness of online versus offline care delivery for most health services is nonexistent.

Return to Top

#### SOCIAL ISOLATION

The impact of Internet use on social isolation and networks has been hotly debated. An early study suggested that Internet use reduced social involvement and psychological well-being (Kraut et al., 1998). Recent data, however, indicate that the opposite may be true. A poll conducted in February 2000 showed that 72 percent of current U.S. Internet users believed that the Internet has made their lives better, while only 2 percent believed it made it worse, and 26 percent thought it had made no difference (Gallup, 2000). A more comprehensive study provided strong evidence that email and the Web have enhanced users' relationships with their family and friends (Pew Internet and American Life Project, 2000b). In this survey, 72 percent of Internet users had visited a relative or friend in the past day, compared to only 61 percent of non-users. In addition, 55 percent of Internet users surveyed thought that email has brought them closer to family members and 59 percent said they now communicate more often with family members since they had an email account. Two thirds of users say email has brought them closer to friends. The longer users had been online, the more likely they felt that email has improved their ties to their families and friends. Furthermore, only 8 percent of Internet users believe that they are socially isolated (defined as "no one or hardly anyone to turn to for support") compared to 18 percent of non-Internet users. Another study showed that more than 90 percent of respondents reported that, since having Internet access at home, household members spend about the same amount or more time together (Cole et al., 2000). Notwithstanding the above, additional study on the impact of the Internet on social isolation is warranted.

# WIDENING THE SOCIOECONOMIC DIVIDE

As discussed earlier, a major concern of the rapid application of technology to society is the impact it will have on existing economic and social inequities. The increasing reliance on using the Internet to disseminate health information and the impending use of the technology to provide health services may leave those without technology access or those without appropriate skills and knowledge at a severe disadvantage. The potential impact of the Internet on socioeconomic gaps warrants serious consideration and further study.

# **INTERNET-RELATED TRENDS** AND THEIR IMPLICATIONS FOR FUTURE EHEALTH TOOLS

#### **Table of Contents**

Foreword

**Preface** 

**Acknowledgements** 

**Executive Summary** 

**Introduction** 

Current Status of the eHealth Sector

Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

Internet Trends Communications Infrastructure Trends and Technologies Application Development Trends Biotechnology and Nanotechnology Trends

Predicting the future of eHealth, as with other emerging technologies, is an imprecise science at best. It is fraught with uncertainty because of the rapid developments in science and technology. At the time of the ARPAnet, which was created as the communication network for military-funded research institutions in 1969, few, if any, individuals envisioned that it would be the precursor to the public Internet of today. The Institute for the Future predicts that consumer-oriented eHealth applications will make the most progress in the next five years (Mittman and Cain, 1999; Cain et al., 2000). Nonetheless, the Institute asserts that progress in clinical aspects of eHealth will be restrained by previous investments in information systems, organizational structures, and incentives for health care professionals.

Rather than speculating on future scenarios, however, it may be helpful to identify and assess major technological and other drivers that are likely to have an impact on eHealth development and adoption in the next five years. Several Internetrelated and other trends and technologies will have a substantial influence on the design, content, functionality, dissemination, and use of future eHealth tools. Although some of these may be quickly subsumed by other emerging technologies, they offer a framework for thinking about how new developments may affect the eHealth sector. Anticipating the likely trends and technologies related to the Internet, communications infrastructure, application development, and biotechnology will help in identifying potential opportunities for proactive investment and policy development to enhance future eHealth tools and technology.

# **INTERNET TRENDS**

#### **Commercialization**

• The commercialization of eHealth will continue and perhaps become even more pervasive, but noncommercial entities will likely have a role in the future eHealth market.

In the early stages of the World Wide Web, health Web sites were predominantly sponsored by universities, nonprofit organizations, and government agencies. Since then, commercial companies have captured most of the eHealth audience. For example, of the top 20 eHealth sites at the end of 2000, only two were not commercial companies (Appendix 2). The commercialization of eHealth, as with other Internet sectors, will continue— at least in the near term— and perhaps become even more pervasive. An analysis of Web content revealed that 83 percent of sites contain commercial content and only 6 percent contain scientific or educational content (Lawrence and Giles, 1999).

The proliferation of eHealth companies in recent years reflects eCommerce-related trends. Consumers are expected to spend \$10 billion online on health-related products by 2004, compared to \$200 million in 1999 (Jupiter Communications, 2000). Of the \$10 billion projected, pharmaceutical sales will account for about \$4.5 billion (45 percent); personal care products for \$2.3 billion (23 percent); nutraceuticals, which includes vitamins and other herbal supplements for \$1.7 billion (17 percent); and over-the-counter products for \$600 million (6 percent). Increasing competition in the eHealth space will spur the continued evolution of business models away from sole dependence on advertising revenue. However, online health-related advertising spending, which was essentially zero in 1996, is projected to grow to about \$265 million in 2002, half of which will be direct-toconsumer advertising by pharmaceutical companies (Jupiter Communications, 1998).

The trend toward increasing commercialization of online health resources, however, does not necessarily mean that the role of noncommercial entities will be minimal in the future eHealth environment. In recent months, many alliances between commercial eHealth companies and nonprofit organizations, especially universities and professional organizations, have been created. This is because academic and professional organizations have a characteristic that is often elusive for many commercial eHealth brands— public recognition as a credible and trusted source of health information and tools.

#### Globalization

• Because the globalization trend means that increasing numbers of eHealth resources will be developed overseas and for global audiences, issues such as communication barriers, cross-cultural factors, and international quality assurance mechanisms will be increasingly important.

The Internet is becoming increasingly global. Of the estimated over 418 million Internet users at the end of 2000, more than 134 million users were in the United States, nearly four times as many as the second leading country, Japan (Computer Industry Almanac, 2001). In 2002, the United States will have about 33 percent of the total users, and that number will further decline to about 30 percent by the end of 2005 (Figure 3). The vast majority of eHealth sites, as with most Web sites, are currently developed by and for English-speaking people. Non-English-speaking users, however, can use PC- or Web-based translation software to translate text on Web pages to their native language. In fact, some search engine portals (e.g., www.altavista.com) provide users with an option of viewing the site contents in one of several different languages within seconds. A major shortcoming of automated translation software is that it is extremely difficult to account for sociocultural differences, regional nuances in language, and varying individual contexts. For example, a Web document that presents the various treatment options for breast cancer would have little relevance to a resident in a developing country or to a recent U.S. immigrant who does not have health insurance, even if it were accurately translated to the native language. Although still relatively few in number, eHealth sites that offer original content for non-English-speaking users, most commonly for Spanish speakers, have emerged in the last few years (e.g., www.noah-health.org, www.salud.com, www.graciasdoctor.com).

The trend toward globalization means that increasing numbers of online health resources will be developed overseas and for global audiences. In addition to obvious communication barriers, such as language, users will need to be cognizant of how crosscultural factors can result in subtle differences in how content is created and presented. It also means that, unless international organizations become more active in quality assurance issues, the quality and relevance of eHealth sites will be increasingly difficult to monitor because there are limited options for legal or regulatory actions against harmful sites hosted in foreign countries. Even if U.S.-based eHealth sites agree to abide by voluntary quality standards, Web sites hosted overseas may not abide by the same standards and they will not be subject to similar national regulations. The World Health Organization's proposal for an Internet domain name ".health" for health Web sites that fulfill certain quality and ethical standards was recently rejected by ICANN, the group charged to oversee the availability of new domain names (World Health Organization, 2000).

**FIGURE 3** Estimated growth in Internet use in North America versus other regions, 1995-2005.



*Note:* Internet users defined as adults > 16 years old reporting weekly usage in 50 countries from 1990 to 1999 and projections for 2000, 2002, and 2005.

*Source:* Computer Industry Almanac, Inc. *North America is the Leading Region for Internet Users According to the Computer Industry Almanac.* August 18, 1999 (updated December 1999). Available at: <u>www.c-i-a.com/199908iu.htm</u>

#### The d Generation

• The digital generation— represented by today's teenagers and children and subsequent generations will demand immediate and constant access to information and support, and will rely heavily on online resources to inform health and other decisions.

Future generations will consider the Internet as an essential, rather than optional, tool for daily living, work, education, and recreation (Tapscott, 1997). The "d" or digital generation— represented by today's teenagers and children— are so immersed in computers, the Internet, and other technologies at school and in the home, that these technologies have become second nature to them. More than 95 percent of public schools had Internet access in 2000 (CEO Forum on Education

and Technology, 2000). The rapid rate of adoption of the Internet by younger generations is reflected in the fact that more than 25 million children ages 2-17 were online in 2000, which is triple the number in 1997 (Grunwald Associates, 2000). Among 9 to 17 year olds, 63 percent prefer to go online rather than to watch TV, and 55 percent would rather go online than talk on the telephone (America Online, 1999). More so than previous generations, it is likely that these and subsequent generations will demand immediate and constant access to information and support, and will rely heavily on online resources to inform health and other decisions. This implies that health communication and social marketing programs, especially those that target young people or risky health behaviors among youth, will need to incorporate a major Internet component. On the health care side, this trend may spur health care organizations with legacy systems to provide Webbased access to their databases as consumers increasingly expect access to both clinical information and administrative/transactional solutions.

Some communities are anticipating a future where the Internet will be woven into community life. One example is the Blacksburg Electronic Village in Blacksburg, Virginia, which is a public-private partnership that has created a virtual town that complements and enhances the physical community (Blacksburg Electronic Village, 2000). Most of the town's residents have been online for several years, and the site includes a major focus on community building, education, and health. As community infrastructure access becomes more convenient and affordable, the development of locally relevant online health resources will be a priority. In communities where Internet access and training is pervasive, market demand for more community– or population-oriented eHealth tools may skyrocket.

#### Peer-To-Peer Networks

• Peer-to-peer networks, which allow individual computers to function as both a server and a client without any central administrator, may enhance certain health activities (e.g., research, information searching), increase the availability of both credible and unsubstantiated information, and potentially threaten the Web portal model.

Shortly after Napster introduced software to facilitate trading of music using MP3 files, it became so popular that many universities banned their students from using it because it substantially slowed campus network speed.<sup>10</sup> Not surprisingly, Napster was sued by a group of entertainment and publishing companies for copyright infringement. Regardless of the litigation's outcome, the peer-to-peer (P2P) approach pioneered by Napster and others is likely to gain further momentum. In fact, since the launch of Napster, a host of P2P software (typically open-source, which allows others to view its source code) has been released and P2P-focused companies have started up (e.g., Gnutella [www.gnutella.wego.com], Freenet [freenet.sourceforge.net/], Flycode [www.flycode.com] ) . Gnutella, for example, allows users to share any form of digital content, not just music. Because Gnutella is a technology rather than a company, it can't be sued and shut down.

The Web is based on client-server architecture— a system where specific computers (servers) are dedicated to providing information to other computers. A P2P network bypasses the Web. In a P2P system, there are no dedicated servers or hierarchy among connected computers. Each computer functions as both a server and a client without any central administrator. P2P software allows each user to designate which files on his or her hard drive are open to the public.

The wild popularity of P2P networks initially stemmed from its ability to freely share entertainment, but this model has advantages over the existing Web in several respects. Perhaps the most intriguing advantage is that it allows for direct queries of content, especially databases, both within and outside of the Web. A P2P network also can locate much more timely information because it directly searches user computer files seconds after they have been created and potentially before they have been uploaded to a Web server. The search itself may run faster because the program searches large numbers of drives simultaneously and can also anticipate where to locate information based on past search requests. A P2P network would also further eliminate the "middleman" in transactions (e.g., broker and auction fees could be eliminated).

In the eHealth arena, P2P networks could be both a boon and a thorn. For example, in biomedical research, a P2P service could allow researchers in fast moving fields such as genetics to instantly post and share findings in designated public folders. P2P networks could also enable more efficient and direct P2P health-related transactions by eliminating the need for dozens of sector specific online exchanges. Some companies are employing P2P technology to facilitate health care provider access to patient information across locations (Chin, 2001c). In the case of consumers searching for health information, they would have access to an even greater range of information sources, both credible and unsubstantiated, than those already available on the Web. In many ways, the P2P concept is more consistent with the original intent of the Internet- to create a decentralized network of users— than the current Web is. This attribute may be especially worrisome and potentially threatening to the business model of eHealth and other portal sites. Whether P2P networks are a passing fad or a serious threat to the existing Web is unclear. But before P2P networking gains serious interest from businesses and major eHealth developers, several major issues will need to be resolved. There are serious security issues in allowing essentially anonymous users access to hard drives. Also, because of its search approach, such P2P searches can clog bandwidth. In addition, the approach will need to be harmonized with existing copyright law and business models.

# COMMUNICATIONS INFRASTRUCTURE TRENDS AND TECHNOLOGIES

#### Broadband

- The growth of broadband Internet access will enable future eHealth applications to use multimedia content, including full motion video.
- When traffic congestion issues on the current Internet are resolved and endto-end quality of service is available, clinical eHealth services, such as realtime medical consultations, will be in high demand.

Current high-speed Internet services available to homes include satellite, cable modem, and DSL (Digital Subscriber Line) service. The availability of these services to a given location may be dependent on the orientation of the house (satellite), cable TV infrastructure (cable modem), or the distance of the user to a central switching office (DSL). From a base of about 4.9 million users at the end of 2000, residential high-speed Internet services may grow to more than 30 million subscribers in 2004 (eMarketer, 2001) (Figure 4). Another study estimates that more than one-third of online households will have a broadband Internet connection by 2005 (Jupiter Research, 2000).





*Source:* eMarketer. *The Broadband Report.* New York, NY: eMarketer, April 2001. Available at: www.emarketer.com/ereports/ebroadband/welcome.html

Soon after the Internet was opened up to commerce and public use, the Internet backbone quickly became congested and is no longer adequate for developing and implementing advanced applications. As a result, two separate but interdependent initiatives were created as test beds for development of next-generation applications. Internet2 (www.internet2.edu) is a consortium led by more than 170 universities working in partnership with more than 60 technology companies to create an advanced network for national research and educational needs. The network that supports Internet2, called Abilene, operates at 2.4 gigabits per second (45,000 times faster than the typical modem). This speed capacity enables 10 sets of encyclopedias to be transmitted over fiber-optic lines in one second. Internet2 is not open to the general public, but project products are expected to filter down for public use. Internet2 also has established a health science workgroup. Next Generation Internet or NGI is the federal government's counterpart to the Internet2 project. Led by the federal government with private sector partners, it is focused on meeting federal agency needs. NGI health-related projects and activities are mostly funded by NIH, particularly the National Library of Medicine. Currently funded health-related NGI applications include real-time telemedicine, diagnostic support tools, and professional education (Howell, 2000).

The technical needs of advanced eHealth applications are more robust than those

for the entertainment, finance, or e-commerce arenas (National Research Council, 2000). In contrast to most business applications, for example, the potential for harm is very real if the infrastructure or software fails. This is because eHealth tools by definition may involve the transmission of data or information that may be used in life-threatening situations. For example, next generation eHealth applications in the area of telemedicine and telehealth will require complete assurance of data security because the consequences of corrupted or lost data during transmission may be severe. In addition, ensuring quality of service (QoS) will be essential for many multimedia eHealth tools that require guaranteed bandwidth and latency to function.

The emergence of broadband Internet service and access implies that future eHealth applications will increasingly provide multimedia content, including full motion video. When traffic congestion issues on the current Internet are resolved and end-to-end quality of service is available, clinical eHealth services, such as realtime medical consultations, will be in high demand. Such services will be accessible at any time and almost anywhere in the world. The emergence of broadband service will also enable developers to widely apply the advantages of multimedia to augment text-based sites and tools with multimedia-based approaches.

Non-technical barriers, however, may limit the spread of multimedia content and tools. These include the additional expenses associated with developing multimedia content and tools, and the need for new models of care delivery for real-time health care consultations. In addition, even if broadband service is available in an area, the cost for high-speed access will likely remain prohibitive for many lower-income families at least in the near term. Therefore, the next debate about the "digital divide" may not be centered on simply access to the Internet, but rather, on the speed and quality of that connection.

#### Wireless Technologies

• The advent of wireless technologies will spur the growth of a new class of mobile eHealth applications for both providers and consumers.

The number of people worldwide with wireless Internet access is relatively small but is expected to grow from 6 million (< 2 percent of Internet users) in 2000 to 484 million by 2005 (Figure 5). By 2003, users of two-way Internet access may account for 60 percent of the U.S. home Internet users (IDC, 2000b). In addition, many industry observers believe that within one to two years, virtually all digital wireless phones shipped will have mobile Internet access. Current consumer demand for wireless Internet services is still relatively weak partly because of the limitations of current wireless access devices, which include small displays and keypads, time-dependent pricing, limited access to online content, and slow access speeds (Strategis Group, 1999). These limitations are being addressed by the industry, but the average transmission speed for initial wireless devices is 9.6Kbps,

which is much slower than the most commonly used dial-up modems (typically 28.8-56Kbps).

FIGURE 5 Growth in estimated number of wireless Internet users worldwide from 2000 through 2005.



Number of Wireless Internet Users Worldwide

Year

Source: Ovum. As quoted by D. Lake. "Wireless Net: Not Yet." The Industry Standard, May 22, 2000. Available at:

www.thestandard.com/research/metrics/display/0,2799,15258,00.html

Emerging technologies, such as 3G (Third Generation) and WAP (Wireless Application Protocol) (<u>www.wapforum.org</u>), however, promise to dramatically scale up demand for wireless access. There has been two generations of mobile phone standards. The first generation standard was introduced in the 1980s and was based on analog technology. The second generation standards (e.g., CDMA, GSM), are based on digital technology, and became available in the 1990s. Different regions and carriers around the world have adopted varying versions of first and second generation technologies, resulting in incompatible wireless phone networks. In the next 5-10 years, carriers are expected to converge toward a common standard for mobile multimedia called 3G, which is based on CDMA technology. 3G promises to deliver broadband mobile communication, including voice, video, graphics, and audio, at speeds of up to 2 Megabits per second (Mbps) or about 40 times faster than an average dial-up modem. Trials of 3G services will be conducted in Japan in 2001. In order for wireless Internet access to succeed, a standard for delivering content to wireless devices is required. WAP performs this function by allowing different mobile devices to access the Internet through a "micro-Web browser." This browser enables Web content to be displayed and formatted for small device screens.

Another potentially disruptive emerging technology is wireless networking, which

is rapidly becoming affordable for home and other non-corporate applications. The bandwidth of the most commonly used wireless LAN standard, IEEE 802.11b or "Wi-Fi" (www.wi-fi.net) is up to 11 Mbps, which is sufficient for voice and video applications over Internet Protocol. Wi-Fi uses the 2.4 GHz wireless spectrum that has been set aside for microwave ovens, cordless phones, and other devices. Some cities, such as Boston, San Francisco, and Seattle have already established wireless networks for public use, and many start-up companies are installing such networks in hotels, airports, campuses, and other locations.

In the next several years, individuals will likely possess multiple electronic devices that are capable of transmitting and receiving data. The upcoming plethora of wireless Internet devices means that these devices will need to communicate with each other and nonmobile equipment to exchange data. "Bluetooth" (www.bluetooth.com), an initiative sponsored by major IT corporations, promises to address this need by enabling wireless devices to communicate with each other using short-range radio frequencies instead of hard wires. Within several years, most Internet access devices including mobile phones, PDAs, portable and workstation PCs, and printers, are likely to have a Bluetooth chip allowing convenient connectivity with other enabled devices.

The advent of wireless Internet access is predicted to spur the growth of a new class of mobile eHealth applications for both providers and consumers. With widespread installation, wireless networks have the potential to dramatically improve access to health information and services. Examples of currently available technology include mobile tools for clinical decision support, scheduling, ordering laboratory tests, and prescribing medications (e.g., www.iscribe.com, www.ephysician.com, www.epocrates.com, www.allscripts.com), using PDAs and digital pagers. For health care providers, emerging wireless technologies may enable access to real-time electronic health records and expert systems at the point of care. On the consumer side, access to critical information and advice at the point in time of need could be enhanced enormously by wireless eHealth tools. For example, an individual contemplating treatment options or another health decision could instantly access tailored advice and decision support tools at the point of need. In addition, wireless devices will facilitate short online transactions, such as scheduling appointments, filling prescriptions, or checking test results. Further down the road, a host of new eHealth applications may be ushered in by wireless monitoring of people and environments through remote biosensors and other devices. Mobile Internet devices will likely complement, rather than replace, the PC as the preferred interface for most Internet users.

#### Non-PC Internet Devices and Appliances

• The trend toward non-PC-centric access will encourage eHealth developers to cater to wider audience segments and spur development for a variety of access devices and formats.

Non-PC Internet devices and appliances (e.g., PDAs and other hand-held communication devices, Web-enabled phones, interactive TV, Web and email terminals, Internet gaming consoles), are relatively low-cost, user friendly devices specifically designed for easy Internet access but lack the computing power of PCs. The number of Internet appliances purchased by consumers is expected to surpass PCs in 2002 (Figure 6). More than 25 million information appliances will be shipped in 2002 compared to 23 million PCs in the United States (IDC, 2000b). By 2005, it is predicted that more than 55 percent of U.S. Internet users will carry out some of their online activities using an Internet appliance (eTforecasts, 2000).

# **FIGURE 6** Estimated number of Internet appliances and PCs shipped by year in the United States.



*Source:* IDC. *Mobile Access to Internet Gains Momentum.* IT Forecaster. Framingham, MA: IDC. March 21, 2000. Available at: <a href="http://www.idc.com/itforecaster/itf2000-03-21.stm">www.idc.com/itforecaster/itf2000-03-21.stm</a>

Traditional communication devices, such as the telephone, are also being deployed as Internet access devices. Some startup companies (e.g., <u>www.quack.com</u>, <u>www.tellme.com</u>, <u>www.heyanita.com</u>) have developed interactive voice portals whereby users call a toll free number and, using advanced voice recognition and synthesis software, request and receive verbal information based on Internet databases (Cleary, 2000). Such portals are currently limited to simple searches (e.g., directions, traffic reports, airline schedules) but represent the beginnings of device-independent voice access.

The trend toward non-PC-centric access has several implications for eHealth. First,

the availability of these devices and appliances will result in a more diverse online audience by allowing more non-PC-literate individuals to use the Internet. In addition, current PC-based users will likely increase their usage of and reliance on the Internet as they employ additional access devices. This suggests that successful eHealth developers will need to cater to wider audience segments. Developers will also need to design applications so that they, or versions thereof, will be accessible through a wide variety of access devices, user interfaces, and formats. In addition, a plethora of Internet-enabled health monitoring devices, such as remote devices to measure blood pressure, blood glucose, and drug concentrations, will also likely be widely implemented.

Return to Top

## **APPLICATION DEVELOPMENT TRENDS**

#### Personalization and Tailoring

• As personalization and tailoring become more common components of eHealth sites and tools, increased online collection and use of potentially sensitive personal health information will raise privacy and data security issues.

Personalization and tailoring, with reference to interactive media, is the practice of dynamically altering content (e.g., information, interactive tools, interfaces, twoway communication) according to the individual profile, preferences, or usage patterns of an individual user. This concept is increasingly being deployed throughout major Web sites to provide users with a more relevant and efficient experience. Personalization algorithms can be based either on stated preferences and personal characteristics of users or on profiles developed from tracking user activity patterns. Among other things, online personalization can enable marketing at the individual level. Not surprisingly, personalization software has been extremely well received by many companies and has become a sizable market. Personalization and tailoring approaches are currently limited by the availability of reliable profile data and the lack of sophisticated, scalable information models that support personalization and tailoring.

The most effective tailoring is based on generally accepted behavior change theory. In several eHealth areas, such as health promotion and disease prevention, it has been shown that providing tailored information is more effective than non-tailored materials (Kreuter et al., 1999; Strecher et al., 1994; Noell et al., 1999). As personalization and tailoring become more commonplace and sophisticated components of eHealth sites and tools, increased online collection and use of

potentially sensitive personal health information will result, thus, raising privacy and data security issues. In addition, the practice of dynamically generating content based on user profiles and characteristics means that the evaluation of online resources will be that much more challenging, because the content, by definition, is not static.

#### XML

• Extensible Markup Language (XML) is enabling the development of innovative eHealth tools that are considerably more powerful and user friendly than what we currently have.

XML was developed in 1998 to address the shortcomings of Hypertext Markup Language (HTML), which is used to code most Web pages. One of the major shortcomings of HTML is that it only describes how a Web browser should arrange text and graphics on a page; it does not describe the page's content. XML tags can be used to describe the meaning of content regardless of its display format. For example, with XML tags for electronic health records, a primary care clinician could email to a reference laboratory a portion of a patient's record that describes the suspected diagnosis of an infectious disease. The laboratory, after confirming the results of testing, could then electronically relay the positive lab results back to the clinician, the insurance company, and the public health department as appropriate. With XML, the various information systems in this loop would be able to interpret and integrate this information. XML not only facilitates document exchange across different computer systems, software programs, access devices, and language barriers, but it also allows for more efficient information processing and searching. One key to implementing XML is that activity-specific interests will have to agree on how they want to represent the information they exchange. Once groups of health professionals can agree on what health XML tags are allowed, how they relate to each other, and how they are processed, a flood of innovative eHealth tools that are considerably more powerful and user friendly than what we currently have will be available.

**ASPs** 

• Application Service Providers (ASPs) may enhance the availability of specialized eHealth tools, but may also result in privacy and data security considerations.

An ASP is a company that supplies online software applications and/or softwarerelated services, usually to other businesses. Typically the ASP develops, owns, maintains, and operates the software on its own servers and makes it available via a Web browser or a "thin client" for a fee, or sometimes for free. Employing this model minimizes the problems and costs associated with businesses or individuals separately maintaining, updating, and expanding functionality of software tools. Another major advantage is that users are not as reliant on the processing and storage capacity of their own computer systems or access devices to take advantage of specialized or complex tools that are processor or storage intensive. Because of the efficiencies garnered through the ASP model, the ASP market has exploded and a flood of companies have entered this area.

Although health-related ASPs have been in existence for many years, the growth of We be nabled applications has several possible implications. Intermediary companies, such as health plans, insurers, and provider groups, will increasingly subscribe to ASP products from specialized companies, which will stake out a specific segment of the eHealth development market (e.g., practice management systems, electronic health records, provider-patient communication) and serve as the developer and disseminator of those tools. This will likely result in privacy and data security considerations. For example, in the case of a health plan that subscribes to an electronic health record ASP, personal health information will likely reside on the ASP's servers unbeknownst to the patient. In fact, a single health plan may subscribe to several ASPs for different software needs, thus, relying on other companies to ensure the security and privacy of potentially sensitive health data. In addition, the inner workings of ASP software will be less visible to end-users because they are one step removed from the development process. On the positive side, the ASP model allows intermediary businesses to focus on their core mission and enables ASPs to develop highly specialized and complex products that may not have been financially viable otherwise because of economies of scale. This advantage could be important for enhancing the availability of future eHealth tools dealing with complex areas, such as genetics and expert systems.

Return to Top

# **BIOTECHNOLOGY AND NANOTECHNOLOGY TRENDS**

#### Genomics

- The decoding of the human genome and its subsequent biomedical advances will likely have as dramatic an impact on health and health care as the Internet will— if not more so.
- As the complexity and volume of genetic knowledge grow, both providers and consumers will become increasingly reliant on information technology to assist them in storing and interpreting the results of genetic testing and evaluating treatment options. As a result, new eHealth tools to support both clinician and consumer decision-making in genetics will be in great demand.

On June 26, 2000, the Human Genome Project and Celera Genomics jointly announced the completion of a draft sequence of the human genome with the exact genetic sequence to be deciphered in a few years.<sup>11</sup> Within this decade, the functions of many genes will be discovered, and new screening and diagnostic tools and treatments will be developed. The decoding of the human genome and its subsequent biomedical advances will likely have as dramatic an impact on health and health care as the Internet will— if not more so. New genetically-based tools will enable individuals to receive preventive interventions and treatments that are tailored to their genetic code, resulting in more effective therapy and less treatment side effects. Gene chips for analyzing gene activity will allow us to distinguish between subtypes of infections and disease processes in ways that are not possible now. Genetic testing will be conducted routinely as part of clinical care and also in non-health care settings, such as the home and workplace.

The sequencing of the human genome and the subsequent unraveling of specific gene functions have spurred the emergence of "personalized" medicine— the science of selecting and optimizing therapies in relation to individual genetic variations. This emerging concept predicts that clinicians will be much more reliant on technology and computational resources to deliver care in the future. The growth of genetic knowledge also has substantial implications for population health and public health research and interventions. For example, genetic epidemiology may enable us to match genetic subpopulations with the most effective public health interventions.

There is little doubt that advances in genomics will also push very controversial issues to the forefront of how genetic information is collected, analyzed, and disseminated. One of the primary issues is the question of who will have access to information about individual genetic predispositions— employers, insurance companies, providers, government agencies, or relatives? Because the complexity and volume of genetic knowledge will be daunting, health care providers, health plans, and consumers will be much more reliant on information technology to assist them in storing and interpreting the results of genetic testing and evaluating treatment options. As a result, new eHealth tools to support both clinician and consumer decision-making in genetics will be in great demand.

## Nanotechnology

• Nanotechnologies, such as cellular or sub-cellular sensors or computers, will generate novel methods and tools for collecting, storing, and analyzing Internet-accessible health data.

Nobel Laureate Dr. Richard Smalley, testifying before Congress, made the bold statement: "The impact of nanotechnology on the health, wealth, and lives of people will be at least the equivalent of the combined influences of microelectronics, medical imaging, computeraided engineering, and man-made polymers developed in this century" (Smalley, 1999).

The term nanotechnology refers to the size of compounds and other structures that are only nanometers (1/1,000,000,000 of a meter) in diameter or roughly the size of biologic molecules, such as proteins. Nanotechnology promises to enhance drug design and drug and gene delivery by enabling diagnosis and clinical interventions on the cellular or sub-cellular level. For example, gene chips now allow genes to be completely characterized molecule by molecule in a few hours- a process that ordinarily took years to complete just several years ago. Such technology will enable the characterization of each individual's genetic profile at a reasonable cost. Some experts predict that, within two to five years, inexpensive hand-held biosensors will allow the detection of a wide range of diseases within minutes from small samples of blood or saliva (Institute for Alternative Futures, undated). Within five to ten years, external biosensors, along with minimally invasive biosensors on the cellular level, may allow for detection of disease processes in their initial stages. It is likely that advances in nanotechnology will help transition us from the era of "wearable" computers (e.g., headset- and wristwatch-integrated PCs) to invivo computers that monitor biological processes and attempt to correct them in real-time. Such sensing systems may ultimately shift the focus of clinical care from treatment to early detection and prevention. In addition, synthetic tissues and organs could be placed in cells to enhance or replace lost function. Regardless of the ultimate path that nanotechnology takes, it is clear that novel methods and tools for collecting, storing, and analyzing data generated by nanotechnology sensors or computers will be needed. Privacy and data security issues will need to be considered as such data will likely reside in secured Internet-accessible databases.

<sup>&</sup>lt;sup>10</sup> MP3 is a compression format that converts music recorded on CDs to small, playable computer files.

<sup>&</sup>lt;sup>11</sup> The Human Genome Project is a federally funded project started in 1990 to sequence the human genome. A consortium of universities conducts its sequencing work and its data is posted on the Internet on a daily basis. Celera Genomics is a commercial company that competed with the public genome effort and seeks to sell information about the sequence to pharmaceutical companies and others to develop therapies.



#### Table of Contents

Foreword

**Preface** 

Acknowledgements

#### **Executive Summary**

**Introduction** 

# Current Status of the eHealth Sector

#### Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

Any of the previously described emerging technologies and trends is singularly powerful. Their convergence could shift many paradigms in health and health care. Potential examples of such converging applications include wireless, subcellular biosensors that monitor individual health parameters in real-time; techniques for meta-analyses of genetic, biophysical, and behavioral information to inform development of personalized health interventions including therapies; and tailored, broadband, interactive multimedia health communications.

What will be the ultimate impact of emerging information and communication technologies on the future of health and health care? It is unclear how these and other upcoming technologies will evolve or how rapidly they will be integrated into health interventions and programs. Undoubtedly, however, as new eHealth technologies are developed and deployed, our capacity and processes to assess and make informed decisions about their appropriate use will be tested.

In the near future, several fundamental societal questions will need to be addressed. What are the policy, ethical, and legal issues around these emerging eHealth technologies? Who will have access to cutting-edge technologies? Who will pay and how much? What should be the standards and guidelines for appropriate use of these technologies? What are the implications of these technologies for the health care and public health systems in terms of quality, access, and costs? Clearly, the impending availability of enhanced Internet access, innovative interactive tools and devices, integrated health information systems, and gene-based screening, diagnostic tools, and therapy, will force further public debate about the central issues of quality, privacy and confidentiality, clinical appropriateness, public policy, cost and financing, and resource distribution.



Table of Contents	Agency for Healthcare Research and Quality. <i>Consumer Health Informatics and Patient Decision-Making. Final Report.</i> Rockville, MD: Agency for Healthcare
Foreword	Research and Quality, 1997. Publication 98-N001.
Preface	Alcatel. "Internet Speed Record Smashed: KPNQwest & Alcatel Quadruple Top Speed for Data Transfer." Paris: Alcatel, May 9, 2000. Available at:
Acknowledgements	www.alcatel.nl/html/nieuws/pers/20000508.shtml
Executive Summary	America Online. <i>America Online/Roper Starch Youth Cyberstudy 1999.</i> New York, NY: America Online/Roper Starch, November 11, 1999. Available at:
Introduction	corp.aol.com/press/roper.html
Current Status of	American Management Association. "More U.S. Firms Checking E-Mail,
the eHealth Sector	Computer Files, and Phone Calls, Says American Management Association Survey." New York, NY: American Management Association, April 14, 2000.
Perspectives of Major	Available at: <a href="http://www.amanet.org/press/research/check_email.htm">www.amanet.org/press/research/check_email.htm</a>
eHealth Stakeholders	
Overview of Major	Arthur Andersen. "Employee Health Benefits Increase in Scope and Cost, Arthur Andersen Survey Finds. Survey of Health and Welfare Benefit Plans 2000."
eHealth Issues	Atlanta, GA: Arthur Andersen, September 7, 2000. Available at:
	www.arthurandersen.com/website.nsf/content/
A Cautionary	MediaCenterNewsDeskHealthandWelfare?OpenDocument
View of eHealth	
Internet-Related Trends and Their Implications	Associated Press. "Town Proves Online Access Isn't Enough." New York, NY: <i>The Wall Street Journal</i> , September 5, 2000. Page A11A.
Key Questions	Atlantic Information Services. "Kaiser Permanente Looks to Become King of Cyberspace." Washington, DC: Atlantic Information Services, Inc., August 29,
for eHealth	2000. Available at: www.aishealth.com/EHealthBusiness/082900.html
References	Bailey S. Testimony of Stephanie B.C. Bailey, MD, MSHSA for the Hearing on
<u>Appendices</u>	<i>Bioterrorism: Our Frontline Response.</i> Before the Subcommittee on Public Health, Education and Medical Readiness Committee on Health, Education, Labor, & Pensions, United States Senate, March 25, 1999. Available at:
	www.naccho.org/advocacydoc175.cfm

Bates D.W., Gawande A.A. "The Impact of the Internet on Quality Measurement." *Health Affairs*. 2000;19(6):104-114. Available at: www.healthaffairs.org/archives\_library.htm

Bell D.S., Fonarow G.C., Hays R.D., Mangione C.M. "Self-Study from Web-Based and Printed Guideline Materials. A Randomized, Controlled Trial Among Resident Physicians." *Annals of Internal Medicine*. 2000; 132(12):938-946.

Berland G.K., Elliot M.N., Morales L.S., Algazy J.I., Karavitz R.L., Broder M.S., et al. "Health Information on the Internet. Accessibility, Quality, and Readability in English and Spanish." *Journal of the American Medical Association*. 2001;285:2612-2621.

Black M., Hussain H. "Hydrazine, Cancer, the Internet, Isoniazid, and the Liver." *Annals of Internal Medicine*. 2000; 133(11):911-913.

Blacksburg Electronic Village. *Blacksburg Electronic Village*. Blacksburg, VA: Virginia Polytechnic Institute and State University, August 2000. Available at: <a href="http://www.bev.net/">www.bev.net/</a>

BrightPlanet. *The "Deep" Web: Surfacing Hidden Value*. Sioux Falls, SD: BrightPlanet.com LLC, July 2000. Available at: 128.121.227.57/download/deepwebwhitepaper.pdf

Brubaker B. "Sensitive Kaiser E-Mails Go Astray." *Washington Post*, August 10, 2000. Page E01. Available at: <u>www.washingtonpost.com/wp-dyn/articles/A64768-</u>2000Aug9.html

Cain M.M., Sarasohn-Kahn J., Wayne J.C. *Health e-People: the Online Consumer Experience*. Menlo Park, CA: Institute for the Future, August 2000. Available at: ehealth.chcf.org/view.cfm?section=Forecasts&itemID=3313

California HealthCare Foundation and the Internet Healthcare Coalition. *Ethics Survey of Consumer Attitudes about Health Web Sites*. Oakland, CA: California HealthCare Foundation, January 2000. Available at: ehealth.chcf.org/view.cfm?section=Consumer&itemID=1740

Centers for Disease Control and Prevention (CDC). "Estimated Expenditures for Essential Public Health Services-Selected States, Fiscal Year 1995." *Morbidity Mortality Weekly Report*. 1997;46:150-152. Available at: www.cdc.gov/epo/mmwr/preview/mmwrhtml/00046330.htm Centers for Disease Control and Prevention. *Supporting Public Health Surveillance through the National Electronic Disease Surveillance System (NEDSS)*. Atlanta, GA: Centers for Disease Control and Prevention, undated. Available at: www.cdc.gov/nchs/otheract/phdsc/presenters/nedss.pdf

Centers for Disease Control and Prevention. *IRM Strategic Plan 2001-2005*. Atlanta, GA: Centers for Disease Control and Prevention, September 18, 1999. Available at: <u>www.cdc.gov/irmo/irmsplan2001.pdf</u>

CEO Forum on Education and Technology. *School Technology and Readiness*. Washington, DC: CEO Forum on Education and Technology, June 2000. Available at: <u>www.ceoforum.org/reports.cfm?RID=4</u>

Chassin M.R., Galvin R.W. "The Urgent Need to Improve Health Care Quality. Institute of Medicine National Roundtable on Health Care Quality." *Journal of the American Medical Association*. 1998;280:1000-5.

Chin T. "Doctors Go Online, But Mostly From Home, Not the Office." *American Medical News*. February 12, 2001a. Available at: <u>www.ama-assn.org/sci-pubs/amnews/pick\_01/tesb0212.htm</u>

Chin T. "Pilot Project to Pay Physicians for E-mail 'Visits'." *American Medical News*. April 9, 2001b. Available at: <u>www.ama-assn.org/sci-</u>pubs/amnews/pick\_01/tesb0409.htm

Chin T. "Peer to Peer: Sharing Patient Data Online." *American Medical News*. March 12, 2001. Available at: <u>www.ama-assn.org/sci-</u> pubs/amnews/pick\_01/tesa0312.htm

Chin T. "The Plugged-In Crowd: How Many Physicians are Online?" *American Medical News*. Nov. 13, 2000. Available at: <u>www.ama-assn.org/sci-pubs/amnews/pick\_00/tesa1113.htm</u>

Cleary S. "Speak and You Shall Receive." *The Wall Street Journal*. September 18, 2000. Page R25.

Cole J., Suman M., Schramm P., van Bel D., Lunn B., Maguire P., Hanson K., Singh R., Aquino, J. *Surveying the Digital Future*. Los Angeles, CA: UCLA Center for Communication Policy, October 2000. Available at: <u>ccp.ucla.edu/ucla-</u> <u>internet.pdf</u> Computer Industry Almanac. U.S. has 33% Share of Internet Users Worldwide Year-end 2000 According to the Computer Industry Almanac. Arlington Heights, IL: Computer Industry Almanac Inc., March 5, 2001. Available at: <u>www.c-i-</u> a.com/200103iu.htm

Cyber Dialogue. *Online Healthcare Consumers Focused on Privacy*. New York: Cyber Dialogue, July 12, 2000. Available at: www.cyberdialogue.com/news/releases/2000/07-12-cch-privacy.html

Darkins A.W., Cary M.A. *Telemedicine and Telehealth*. Principles, Policies, Performance, and Pitfalls. New York: Springer Publishing Company, 2000.

Dayton C.S., Ferguson J.S., Hornick D.B., Peterson M.W. "Evaluation of an InternetBased Decision-Support System for Applying the ATS/CDC Guidelines for Tuberculosis Preventive Therapy." *Medical Decision Making*. 2000 Jan-Mar;20(1):1-6.

Delio M. "A City with a Broadband Future." San Francisco, CA: *Wired*. Aug. 22, 2000. Available at: <u>www.wired.com/news/culture/0,1284,38346,00.html</u>

Eng T.R., Gustafson D., Henderson J., Jimison H., Patrick K., for the Science Panel on Interactive Communication and Health. "Introduction to Evaluation of Interactive Health Communication Applications." *American Journal of Preventive Medicine*. 1999;16:10-15. Available at: www.health.gov/scipich/pubs/introIHC.htm

Eng T.R., Maxfield A., Patrick K., Deering M.J., Ratzan S., Gustafson D. "Access to Health Information and Support: a Public Highway or a Private Road?" *Journal of the American Medical Association*. 1998;280:1371-75. Available at: jama.ama-assn.org/issues/v280n15/abs/jpp80018.html

eMarketer. *The Broadband Report*. New York, NY: eMarketer, April 2001. Available at: <u>www.emarketer.com/ereports/ebroadband/welcome.html</u>

Eysenbach G., Yihune G., Lampe K., Cross P., Brickley D. "Quality Management, Certification and Rating of Health Information on the Net with MedCERTAIN: Using a medPICS/RDF/XML Metadata Structure for Implementing eHealth Ethics and Creating Trust Globally." *Journal of Medical Internet Research*. 2000;2 (3/suppl 2):e1. Available at: www.jmir.org/2000/3/suppl2/el/index.htm

eTforecasts. *By 2005 55% of U.S. Internet Users Will Use Web Appliances*. Buffalo Grove IL, June 12, 2000. <u>www.etforecasts.com/pr/pr600.htm</u>

Federal Communications Commission. *Deployment of Advanced Telecommunications Capability: Second Report.* Federal Communications Commission, August 2000. Available at: www.fcc.gov/Bureaus/Common\_Carrier/Orders/2000/fcc00290.pdf

Federal Trade Commission. "Operation Cure.all" Targets Internet Health Fraud. Washington, DC: Federal Trade Commission, June 24, 1999. Available at: www.ftc.gov/opa/1999/9906/opcureall.htm

Federal Trade Commission. *Federal Trade Commission Issues Report on Online Profiling*. Washington, DC: Federal Trade Commission, July 27, 2000. Available at: <a href="https://www.ftc.gov/opa/2000/07/onlineprofiling.htm">www.ftc.gov/opa/2000/07/onlineprofiling.htm</a>

Fried B.M., Weinreich G., Cavalier G.M., Lester K.J. "E-Health: Technologic Revolution Meets Regulatory Constraint." *Health Affairs*. 2000;19(6):124-131. Available at: <a href="https://www.healthaffairs.org/archives\_library.htm">www.healthaffairs.org/archives\_library.htm</a>

Gallup. *Americans Say Internet Makes Their Lives Better*. Princeton, NJ: Gallup News Service, February 23, 2000. Available at: www.gallup.com/poll/releases/pr000223.asp

Gellman R. Analysis of the Marketing Provisions of the HIPAA Privacy Rules. Phoenix Health Systems, 2001. Available at: www.hipaadvisory.com/action/privacy/marketing.htm

Goldman J., Hudson Z., Smith R.M. *Report on the Privacy Policies and Practices of Health Web Sites*. Oakland, CA: California Healthcare Foundation. January 2000. Available at: <u>ehealth.chcf.org/view.cfm?section=Privacy&itemID=1750</u>

Goldman J., Hudson Z. "Virtually exposed: privacy and e-Health." *Health Affairs*. 2000;19(6):140-148. Available at: <u>www.healthaffairs.org/archives\_library.htm</u>

Goldsmith J. "The Internet and Managed Care: a New Wave of Innovation." *Health Affairs*. 2000;19(6):42-56. Available at: www.healthaffairs.org/archives\_library.htm

Government Accounting Office. Critical Infrastructure Protection. "ILOVEYOU" Computer Virus Highlights Need for Improved Alert and Coordination Capabilities. Washington, DC: GAO, May 18, 2000. Available at: http://www.gao.gov/new.items/ai00181t.pdf

Graber M.A., Roller C.M., Kaeble B. "Readability Levels of Patient Education Material on the World Wide Web." *Journal of Family Practice*. 1999;48:58-61.

Grunwald Associates. *Children, Families and the Internet 2000.* San Mateo, CA: Grunwald Associates, June 7, 2000. Available at: <a href="http://www.grunwald.com/survey/survey\_content.html">www.grunwald.com/survey/survey\_content.html</a>

Gustafson D.H., Hawkins R., Boberg E.W., Pingree S., Serlin R., Graziano F., et al. "Impact of Patient Centered Computer-Based Health Information and Support System." *American Journal of Preventive Medicine*. 1999;16:1-9.

Gustafson D.H., Robinson T.N., Ansley D., Adler L., Brennan P.F., for the Science Panel on Interactive Communication and Health. "Consumers and Evaluation of Interactive Health Communication Applications." *American Journal of Preventive Medicine*. 1999;16:23-29. Available at: www.health.gov/scipich/pubs/consumers.htm

Handler J.A., Gillam M., Wang E.E., Feied C.F., Yarnold P.R., Bose S., Smith M.S. "Computers and Connectivity in Illinois Emergency Departments." *Academic Emergency Medicine*. 1999;6(12):1249-1254.

Harris Interactive. *Explosive Growth of "Cyberchondriacs" Continues*. New York, NY: Harris Interactive, August 11, 2000a. Available at: www.harrisinteractive.com/harris\_poll/index.asp?PID=104

Harris Interactive. *Harris Interactive Study Reveals a Lack of Information Technology Use in Medicine*. Rochester, NY: Harris Interactive, March 28, 2000b. Available at: www.harrisinteractive.com/news/index.asp?NewsID=78&HI election=All

Harris Interactive. "New Data Show Internet, Website and Email Usage by Physicians All Increasing." *Health Care News*. 1(8), February 26, 2001. Available at: <u>www.harrisinteractive.com/about/healthnews/</u> HI\_HealthCareNews2001Vol1\_iss8.pdf

Healthcare Business. "New Directions in Employer Sponsored Health Care." *Healthcare Business*. May 2000. Available at: www.healthcarebusiness.com/archives/healthcarebusiness/0500/rt-intro.html

Healthcare Informatics. "News and Trends. Completing the Disease-Management Loop." *Healthcare Informatics*. August 2000. Available at: <u>www.healthcare-informatics.com/issues/2000/08\_00/trends.htm</u>

Healtheon. As reported by Bennett A. in: "Surveys Find More Physicians Online" *Family Practice Management*. 1999;6:50. Available at: www.aafp.org/fpm/990600fm/contents.html

Health Hero Network, Inc. *Pacificare CHF Disease Management Program, Powered By Health Hero, Shows Significant Reductions in Hospital Admissions.* Health Hero Network, Inc. New York, NY, December 5, 2000. Available at: www.hhn.com/corporate/news/12\_05\_00.html

Health Resources and Services Administration (HRSA). *Federal Telemedicine Directory 1998*. Rockville, MD: HRSA. Available at: telehealth.hrsa.gov/jwgt/teldirect98/index.html

Health on the Net Foundation. *Health on the Net Foundation Code of Conduct*. Geneva, Switzerland, April 1997. Available at: www.hon.ch/HONcode/Conduct.html

Henderson J., Noell J., Reeves T., Robinson T.N., Strecher V., for the Science Panel on Interactive Communication and Health. "Developers and Evaluation of Interactive Health Communication Applications." *American Journal of Preventive Medicine*. 1999;16:30-34. Available at: www.health.gov/scipich/pubs/developers.htm

Hi-Ethics. *Health Internet Ethics: Ethical Principles for Offering Internet Health Services to Consumers.* May 2000. Available at: www.hiethics.org/Principles/index.asp

Howell K. Presentation to MIT Club of Washington. National Coordination Office for Computing, Information, and Communications. January 11, 2000. Available at: <a href="http://www.ngi.gov/talks/">www.ngi.gov/talks/</a>

IDC. *Email Deluge Continues with No End in Sight*. Framingham, MA: IDC. October 10, 2000a. Available at: www.idc.com:8080/software/press/PR/SW101000pr.stm

IDC. *Mobile Access to Internet Gains Momentum*. IT Forecaster. Framingham, MA: IDC. March 21, 2000b. <u>www.idc.com/itforecaster/itf2000-03-21.stm</u>

Inktomi. *Web Surpasses One Billion Documents*. Foster City, CA: Inktomi, January 18, 2000. Available at: <a href="http://www.inktomi.com/new/press/2000/billion.html">www.inktomi.com/new/press/2000/billion.html</a>

Institute for Alternative Futures. *Focused Study on Biotechnology and Nanotechnology*. Alexandria, VA: Institute for Alternative Futures. Not dated. Available at: <u>www.altfutures.com/news/pr\_bionano.htm</u>

Institute of Medicine. *To Err Is Human: Building a Safer Health System*. L. Kohn, J. Corrigan, M. Donaldson, Editors. Institute of Medicine Washington, DC: National Academy Press, 1999. Available at: <u>books.nap.edu/catalog/9728.html</u>

International Narcotics Control Board. *Internet Shopping: Trafficking Goes Online*. Annual Report, Press Release 4. Vienna, Austria, February 21, 2001. Available at: <u>www.incb.org/e/ind\_ar.htm</u>

Internet Healthcare Coalition. *eHealth Code of Ethics*. May 2000. Available at: www.ihealthcoalition.org/ethics/ehcode.html

Jimison H.B., Adler L., Coye M., Mulley Jr A., Eng T.R., for the Science Panel on Interactive Communication and Health. "Health Care Providers and Purchasers and Evaluation of Interactive Health Communication Applications." *American Journal of Preventive Medicine*. 1999;16:16-22. Available at: www.health.gov/scipich/pubs/providers.htm

Joy B. "Why the Future Doesn't Need Us." *Wired*, April 2000. Available at: www.wired.com/wired/archive/8.04/joy.html

Jupiter Communications. *Toward Health Portals: Market Conditions Ripe for Rise of Content/Affinity Portals*. New York, NY: Jupiter Communications, 1998.

Jupiter Communications. Internet Health Commerce to Soar to \$10 Billion, but Current Offerings Don't Deliver on Consumer Convenience. Players Must Ally or Die To Enable Content, Commerce and Service Solutions. New York, NY: Jupiter Communications, January 26, 2000. Available at: www.jup.com/company/pressrelease.jsp?doc=pr000126

Jupiter Research. *More Than One in Three U.S. Online Households Will Connect Via Broadband in 2005, Jupiter Research Says.* New York, NY: November 1, 2000. Available at: <a href="https://www.jup.com/company/company\_profile.jsp">www.jup.com/company/company\_profile.jsp</a>

Kaiser Family Foundation. *Is There A Managed Care "Backlash?"* Washington, DC: Kaiser Family Foundation, November 5, 1997. Available at: www.kff.org/content/archive/1328/mcarepr.html

Kassirer J.P. "Patients, Physicians, and the Internet." *Health Affairs*. 2000;19(6):115-123. Available at: <u>www.healthaffairs.org/archives\_library.htm</u>

Kim P., Eng T.R., Deering M.J., Maxfield A. "Published Criteria for Evaluating HealthRelated Web Sites: Review." *British Medical Journal*. 1999;318:647-649. Available at: <u>www.bmj.org/cgi/content/full/318/7184/647</u>

Klausner J.D., Wolf W., Fischer-Ponce L., Zolt I., Katz M.H. "Tracing a Syphilis Outbreak Through Cyberspace." *Journal of the American Medical Association*. 2000;26;284(4):447-9.

Kleinke J.D. "Vaporware.com: The Failed Promise of the Health Care Internet." *Health Affairs*. 2000;19(6):57-71. Available at: www.healthaffairs.org/archives\_library.htm

Kraut R., Patterson M., Lundmark V., Kiesler S., Mukopadhyay T., Scherlis W. " Internet Paradox. A Social Technology that Reduces Social Involvement and Psychological Well-Being? *American Psychologist*. 1998;53(9):1017-1031.

Kreuter M.W., Strecher V.J., Glassman B. "One Size Does Not Fit All: the Case for Tailoring Print Materials." *Annals of Behavioral Medicine*. 1999;21(4):276-283.

Lawrence S., Giles C.L.. "Accessibility and Distribution of Information on the Web." *Nature*. 1999;400(6740):107-109.

Lazarus W., Mora F. Online Content for Low-Income and Underserved Americans: the Digital Divide's New Frontier. Washington, DC: Children's Partnership, March 2000. Available at: <a href="http://www.childrenspartnership.org/">www.childrenspartnership.org/</a>

Levit K, Cowan C., Lazenby H., Sensenig A., McDonnell P., Stiller J., Martin A. "Health Spending in 1998: Signals of Change. The Health Accounts Team." *Health Affairs*. 2000;19(1):124-132.

Li L., Irvin E., Guzman J., Bombardier C. "Surfing for Back Pain Patients: The Nature and Quality of Back Pain Information on the Internet." *Spine*. 2001;26(5):545-557.

Marsh A., Kauranne T., Zahlmann G., Emmen A., and Versweyveld L. "The Emergence of Virtual Medical Worlds." *Proceedings of High Performance Computing and Networking: 7th International Conference*. Springer-Verlag, Berlin 1999:909-11.

McMullin S.T., Reichley R.M., Watson L.A., Steib S.A., Frisse M.E., Bailey T.C.. "Impact of a Web-Based Clinical Information System on Cisapride Drug Interactions and Patient Safety." *Archives of Internal Medicine*. 1999;159(17):2077-2082

Mechanic D., Rosenthal M. "Responses of HMO Medical Directors to Trust Building in Managed Care." *Milbank Quarterly*. 1999;77:283-303, 273. Available at: <u>www.milbank.org/quarterly/7703feat.html</u>

Media Metrix and Jupiter Communications. *Women Outpace Men Online in Number and Growth Rate According To Media Metrix and Jupiter Communications*. New York, NY: Jupiter Communications, Media Metrix, August 9, 2000. Available at: www.jup.com/company/company\_profile.jsp MedicAlert Foundation. *Gallup Survey Finds Most Americans Shun Using Internet for Personal Health Information*. Turlock, CA: MedicAlert Foundation, November 13, 2000. Available at: www.medicalert.org/releaselatest.html

Merck. *Merck & Co., Inc. Announces Plan to Invest up to \$100 Million in Capital in Emerging Businesses.* Whitehouse Station, NJ: Merck, November 28, 2000. Available at: <a href="https://www.merck.com/newsroom/press\_releases/112800.html">www.merck.com/newsroom/press\_releases/112800.html</a>

Mittman R., Cain M. *The Future of the Internet in Health Care: Five Year Forecast*. California Healthcare Foundation, January 1999. Available at: www.iftf.org/html/iftflibrary/technology/internethealth.pdf

National Center for Biotechnology Information. *GenBank Overview*. Bethesda, MD: National Institutes of Health, 2001. Available at: www.ncbi.nlm.nih.gov/Genbank/GenbankOverview.html

National Committee on Vital and Health Statistics. *Toward a National Health Information Infrastructure*. Washington, DC: National Committee on Vital and Health Statistics, June 20, 2000a. Available at: <u>ncvhs.hhs.gov/NHII2kReport.htm</u>

National Committee on Vital and Health Statistics. *Report to the Secretary of the U.S. Department of Health and Human Services on Uniform Data Standards for Patient Medical Record Information.* Washington, DC: National Committee on Vital and Health Statistics, July 6, 2000b. Available at: www.hipaadvisory.com/regs/ncvhsexecsum.htm

National Institutes of Health. *Small Business Innovation Research (SBIR) Program*. Bethesda, MD: NIH, 2000. Available at: grants.nih.gov/grants/funding/sbi.htm#sbir

National Library of Medicine (NLM). *Testimony of Dr. Donald AB Lindberg, Director, National Library of Medicine to the House Appropriations Sub-Committee on Labor, HHS and Education.* March 18, 1998. Available at: www.nlm.nih.gov/pubs/staffpubs/od/budget99.html

National Public Radio (NPR). NPR, Kaiser Family Foundation, and Harvard University Kennedy School of Government Technology Survey. Washington, DC: NPR, February 2000. Available at: www.npr.org/programs/specials/poll/technology/

National Research Council, Committee on Enhancing the Internet for Health Applications. *Networking Health: Prescriptions for the Internet*. Washington, DC: National Academy Press, 2000. Available at: www.nap.edu/books/0309068436/html/ National Research Council, Committee on Maintaining Privacy and Security in Health Care Applications of the National Information Infrastructure. *For the Record: Protecting Electronic Health Information*. Washington, DC: National Academy Press, 1997. Available at: <u>www.nap.edu/readingroom/books/ftr/</u>

National Telecommunications and Information Administration, Rural Utilities Service. Advanced Telecommunications in Rural America: *The Challenge of Bringing Broadband Service to All Americans*. Washington, DC: National Telecommunications and Information Administration, Rural Utilities Service, April 2000. Available at: www.ntia.doc.gov/reports/ruralbb42600.pdf

National Telecommunications and Information Administration. *Falling Through the Net, Toward Digital Inclusion*. Washington, DC: National Telecommunications and Information Administration, October 2000. Available at: <a href="http://www.ntia.doc.gov/ntiahome/digitaldivide/">www.ntia.doc.gov/ntiahome/digitaldivide/</a>

National Work Group on Literacy and Health. "Communicating with Patients Who Have Limited Literacy Skills. Report of the National Work Group on Literacy and Health." *Journal of Family Practice*. 1998;46:168-175.

Nie N.H., Erbring L. *Internet and Society: a Preliminary Report*. Palo Alto, CA: Stanford Institute for the Quantitative Study of Society, February 17, 2000. Available at: <u>www.stanford.edu/group/siqss/Press\_Release/Preliminary\_Report-4-</u>21.pdf

Nielsen//NetRatings. Internet Penetration Reaches 60 Percent in the U.S., According to Nielsen//NetRatings; More than 168 Million People Have Internet Access. New York, NY: Nielsen//NetRatings, February 28, 2001. Available at: 209.249.142.22/press\_releases/PDF/pr\_010228.pdf

Noell J., Glasgow R. "Interactive Technology Applications for Behavioral Counseling: Issues and Opportunities for Health Care Settings." *American Journal of Preventive Medicine*. 1999;17:269-274.

NUA. *How Many Online?* Dublin, Ireland: NUA Ltd., 2000. Available at: www.nua.ie/surveys/how\_many\_online/index.html

O'Connor G.T., Quinton H.B., Traven N.D., Ramunno L.D., Dodds T.A., Marciniak T.A., Wennberg J.E.. "Geographic Variation in the Treatment of Acute Myocardial Infarction: the Cooperative Cardiovascular Project." *Journal of the American Medical Association*. 1999;281:627-33. Available at: jama.amaassn.org/issues/v281n7/abs/joc81109.html O'Harrow R. "Firm Tracking Consumers on Web for Drug Companies." Washington, DC: *Washington Post*, August 15, 2000. Page E01. Available at: <u>www.washingtonpost.com/wp-dyn/business/specials/privacy/</u> robertoharrow/A25494-2000Aug14.html

Patrick K., Robinson T.N., Alemi F., Eng T.R., for the Science Panel on Interactive Communication and Health. "Policy Issues Relevant to the Evaluation of Interactive Health Communication Applications." *American Journal of Preventive Medicine*. 1999;16:35-42. Available at: www.health.gov/scipich/pubs/policy.htm

Pew Internet and American Life Project. *The Online Health Care Revolution: How the Web Helps Americans Take Better Care of Themselves*. Washington, DC: Pew Research Center, November 26, 2000a. Available at: www.pewinternet.org/reports/toc.asp?Report=26

Pew Internet and American Life Project. *Tracking Online Life: How Women Use the Internet to Cultivate Relationships with Family and Friends*. Washington, DC: Pew Research Center, May 10, 2000b. Available at: www.pewinternet.org/reports/toc.asp?Report=11

PITAC. *President's Information Technology Advisory Committee*. Washington, DC: National Coordination Office for Computing Information, 2001. Available at: <u>www.ccic.gov/ac/intro</u>

Pro-Change Behavior Systems. *Impacts on Health Behavior Change of Health.com Programs.* West Kingston, RI: Pro-Change Behavior Systems, Inc., February 2001.

Public Health Functions Steering Committee. *Public Health in America*. Washington, DC: U.S. Department of Health and Human Services, Fall 1994. Available at: <u>www.health.gov/phfunctions/public.htm</u>

Rafter M.V. "Trust or Bust?" San Francisco, CA: *The Industry Standard*, March 6, 2000. Available at: <u>www.thestandard.com/article/0,1902,12445,00.htm</u>

Rickert A. *The Dollar Divide: Demographic Segmentation and Web Usage Patterns by Household Income*. New York: Media Metrix. August 21, 2000. Available at: www.mediametrix.com/data/MMXI-USHHI-0600.pdf

Robinson J.C. "Financing the Health Care Internet." *Health Affairs*. 2000;19(6):72-88. Available at: <a href="http://www.healthaffairs.org/archives\_library.htm">www.healthaffairs.org/archives\_library.htm</a>

Robinson T.N., Patrick K., Eng T.R., Gustafson D., for the Science Panel on Interactive Communication and Health. "An Evidence-Based Approach to Interactive Health Communication: A Challenge to Medicine in the Information Age." *Journal of the American Medical Association*. 1998;280:1264-1269. Available at: www.health.gov/scipich/pubs/jama98.htm

Seattle Times. "Hacker Steals Files on Patients from UW." *Seattle Times,* December 9, 2000. Page B1. Available at: <u>archives.seattletimes.nwsource.com/cgi-bin/texis/web/vortex/display?slug=hackers</u> <u>09m&date=20001209&query=university+washington+hack%2A</u>

Shiver J. Jr. "More Firms Use Software to Spy on Workers." *Los Angeles Times,* October 14, 1999. Available at: seattletimes.nwsource.com/news/technology/html98/moni\_19991012.html

Shortliffe E.H. "Networking Health: Learning From Others, Taking the Lead." *Health Affairs*. 2000;19(6):9–22. Available at: www.healthaffairs.org/archives\_library.htm

Sittig D.F., King S., Hazlehurst B.L. "A Survey of Patient-Provider E-mail Communication: What Do Patients Think?" *International Journal of Medical Informatics*. 2001;61(1):71-80.

Siwolop S. "Back Pain? Arthritis? Step Right Up to the Mouse." *New York Times,* January 7, 2001. Section 3, Page 10. Available at: <a href="https://www.nytimes.com/2001/01/07/technology/07VITA.html">www.nytimes.com/2001/01/07/technology/07VITA.html</a>

Smalley R. *Prepared Statements for House Science Committee, Subcommittee on Basic Research,* June 22, 1999. Available at: www.house.gov/science/106\_hearing.htm

Smith M.S. *Report for Congress Internet Privacy – Protecting Personal Information: Overview and Pending Legislation.* Washington, DC: Congressional Research Service. Updated October 3, 2000. Available at: <u>www.cnie.org/nle/st-</u> <u>43.html</u>

Smith S., Heffler S., Freeland M. "The Next Decade of Health Spending: A New Outlook. The National Health Expenditures Projection Team." *Health Affairs*. 1999;18(4):86-95.

SPICH (Science Panel on Interactive Communication and Health). *Wired for Health and Well-Being: the Emergence of Interactive Health Communication*. Eng T.R., Gustafson D.H., editors. Washington, DC: U.S. Department of Health and Human Services, April 1999. Available at: <u>www.health.gov/scipich</u> Stoloff P.H., Garcia F.E., Thomason J.E., Shia D.S. "A Cost-Effectiveness Analysis of Shipboard Telemedicine." *Telemedicine Journal*. 1998;4(4):293-304.

Stone T.W., Jumper J.M. "Information About Age-Related Macular Degeneration on the Internet." *Southern Medical Journal*. 2001;94(1):22-25.

Strategis Group. *Third Generation Wireless: Strategies and Forecasts for Global Markets.* Washington, DC: The Strategis Group, December 1999.

Strecher V.J., Kreuter M., Den Boer D.J., Kobrin S., Hospers H.J., Skinner C.S. "The Effects of Computer-Tailored Smoking Cessation Messages in Family Practice Settings." *Journal of Family Practice*. 1994;39(3):262-270.

Suarez-Almazor M.E., Kendall C.J., Dorgan M. "Surfing the Net– Information on the World Wide Web for Persons with Arthritis: Patient Empowerment or Patient Deceit?" *Journal of Rheumatology*. 2001;28(1):185-191.

Tapscott D. *Growing Up Digital: The Rise of the Net Generation*. McGraw-Hill, New York, NY, 1997. More information available at: <u>www.growingupdigital.com/</u>

Tate D.F., Wing R.R., Winett R.A. "Using Internet Technology to Deliver a Behavioral Weight Loss Program." *Journal of the American Medical Association*. 2001;285:1172-1177. Available at: jama.ama-assn.org/issues/v285n9/abs/joc01569.html

The White House. *The Clinton-Gore Administration: A National Call to Action to Close the Digital Divide*. Washington, DC: Office of the Press Secretary, April 4, 2000.

TRUSTe. *Hi-Ethics and TRUSTe Announce Rigorous New E-Health Seal.* Washington, DC: TRUSTe, December 12, 2000. Available at: www.truste.org/about/about\_hiethics.html

U.S. Census Bureau. *Health Insurance Coverage: 1998.* Washington, DC: U.S. Census Bureau, October 28, 1999. Available at: www.census.gov/hhes/hlthins/hlthin98.html

U.S. Court of Appeals. *Opinion of U.S. Court of Appeals for the Third Circuit, No.* 99-1324, June 22, 2000. Available at: www.epic.org/free\_speech/copa/3d\_cir\_opinion.html

U.S. Department of Health and Human Services. *Final Rule: Privacy Standards*. Washington, DC: U.S. Department of Health and Human Services, December 28, 2000a. Available at: aspe.os.dhhs.gov/admnsimp/
U.S. Department of Health and Human Services. *Healthy People 2010*. Washington, DC: Government Printing Office, November 2000b. Available at: www.health.gov/healthypeople/

U.S. Department of Health and Human Services. *HHS Announces Electronic Standards to Simplify Health Care Transactions*. Washington, DC: U.S. Department of Health and Human Services, Aug. 11, 2000c. Available at: www.hhs.gov/news/press/2000pres/20000811.html

U.S. Department of Housing and Urban Development. *Neighborhood Networks*. Washington, DC: U.S. Department of Housing and Urban Development, 2000. Available at: <a href="https://www.hud.gov/nnw/nnwindex.html">www.hud.gov/nnw/nnwindex.html</a>

U.S. Internet Council. *State of the Internet: USIC's Report on Use & Threats in 1999.* Washington, DC: U.S. Internet Council, 1999. Available at: <a href="https://www.usic.org/">www.usic.org/</a>

Weisbord S.D., Soule J.B., Kimmel P.L. "Poison On Line— Acute Renal Failure Caused by Oil of Wormwood Purchased Through the Internet." *New England Journal of Medicine*. 1997; 337:825-827.

Winker M.A., Flanagin A., Chi-Lum B., White J., Andrews K., Kennett R.L., DeAngelis C.D., Musacchio R.A. "Guidelines for Medical and Health Information Sites on the Internet: Principles Governing AMA Web Sites." *Journal of the American Medical Association*. 2000;283(12):1600-1606. Available at: jama.amaassn.org/issues/v283n12/ffull/jsc00054.html

Winzelberg A.J., Eppstein D., Eldredge K.L., Wilfley D., Dasmahapatra R., Dev P., Taylor C.B. "Effectiveness of an Internet-Based Program for Reducing Risk Factors for Eating Disorders." *Journal of Consulting Clinical Psychology*. 2000;68(2):346-350.

Wit Capital. *eHealth 2000: Healthcare and the Internet in the New Millennium*. New York, NY: Wit Capital, January 31, 2000. Available at: www.witcapital.com/research/reports/ehlt\_20000131/

World Economic Forum. *Global Digital Divide Initiative*. Geneva, Switzerland: World Economic Forum, undated documents. Available at: www.weforum.org/digitaldivide.nsf/index

World Health Organization. *Proposal to ICANN for .health Internet Top Level Domain*. Geneva: World Health Organization, October 2, 2000. Available at: www.icann.org/tlds/health1/WHO-E-TLD-Policies.htm



Table of Contents	APPENDIX 1 - eHealth-related information resources. APPENDIX 2 - Comparative Summary of Most Popular eHealth Sites.
Foreword	APPENDIX 3 - Foundations with explicit interest in information and communication
<u>Preface</u>	technology issues. APPENDIX 4 - Venture capital funds with a specific interest in eHealth-related investments.
Acknowledgements	<b>APPENDIX 5</b> - Non-profit organizations with major eHealth-related activities.
Executive Summary	
Introduction	APPENDIX 1 eHealth-related information resources.
Current Status of the eHealth Sector	<i>eHealth-Related Publications and Newsletters</i> Most of the following publications are free but some are only available by subscription.
Perspectives of Major eHealth Stakeholders	E-Care Management News ( <u>www.bhtinfo.com/newsletter.htm</u> )
Overview of Major eHealth Issues	eHealth Reports ( <u>ehealth.chcf.org/</u> )
A Cautionary	eHealthcarebusiness.com (www.ehealthcarebusiness.com/cda/HomePage.asp)
View of eHealth	E-Healthcare Connections (www.ehealthcareconnections.com)
Internet-Related Trends and Their Implications	eHealthcare News ( <u>www.muhealth.org/~news/eHealth/4_2000.shtml</u> )
Key Questions	eHealthcare Strategy & Trends ( <u>www.strategichealthcare.com/ehealth.html</u> )
for eHealth	Healthcare Informatics Magazine ( <u>www.healthcare-informatics.com/index.htm</u> )
<u>References</u>	iHealthcare Weekly ( <u>www.ihealthcareweekly.com</u> )
<u>Appendices</u>	Interactive Healthcare Report (info2.graphiced.com/products.html)
	Internet Healthcare Strategies ( <u>www.corhealth.com/IHS.html</u> )

Medical Computing Today (www.medicalcomputingtoday.com/index.html)

Medicine on the Net (<u>www.corhealth.com/motn/MOTNHome4.asp</u>)

TelehealthNet (telehealth.net/interviews/)

Telehealthonline (telehealth.calhealth.org)

Telemedicine Today (<u>www.telemedtoday.com</u>)

The Informatics Review (www.informatics-review.com)

Wit SoundView's Wisdom on eHealth (<u>www.witsoundview.com/research/reports\_industry.jsp?</u> <u>Industry=ehealth&Name=eHealth</u>)

WR Hambrecht & Co (www.wrhambrecht.com/research/coverage/ehealth/index.html)

**Peer-Reviewed Journals that Frequently Publish eHealth-Related Articles** Many of these online journals require a subscription for full text access.

American Journal of Preventive Medicine (www.meddevel.com/site.mash?left=/library.exe&m1=1&m2=1&right=/ library.exe&action=home&site=AJPM&jcode=AMEPRE)

British Medical Journal (www.bmj.com)

Bulletin of the Medical Library Association (www.mlanet.org/publications/bmla/index.html)

Computers in Biology and Medicine (www.elsevier.nl/inca/publications/store/3/5/1/)

Health Affairs (www.healthaffairs.org)

International Journal of Medical Informatics (www.elsevier.co.jp/inca/publications/store/5/0/6/0/4/0/)

Journal of Health Communication (www.aed.org/JHealthCom/)

Journal of Informatics in Primary Care (www.phcsg.org.uk/informatics/index.htm)

Journal of Medical Internet Research (www.jmir.org/index.htm)

Journal of the American Medical Association (jama.ama-assn.org)

Journal of the American Medical Informatics Association (www.jamia.org)

Medical Informatics and the Internet in Medicine (www.tandf.co.uk/journals/frameloader.html? http://www.tandf.co.uk/journals/tf/14639238.html)

Medscape General Medicine (<u>www.medscape.com/Medscape/GeneralMedicine/</u> journal/public/mgm.journal.html)

Directories of eHealth-Related Conferences and Meetings

www.amia.org/resource/conf&meetings/f2.html

www.telemedtoday.com/website99/portals/conference\_calendar.htm

www.ehto.org/ikb/events/

telehealth.net/calendar/events/Telemed.html

www.medicalcomputingtoday.com/0listconcal.html

# Appendix 2 Comparative summary of most popular eHealth sites.

This is a summary profile of the most widely used health Web sites in the United States. The following chart provides a general idea of the reach, scope, features, and quality indicators of each site. Web site characteristics that were assessed include: market reach, target audience, purpose, content and features, privacy and security protections, editorial process and quality assurance, and accessibility.

Some of the data in the following table should be considered with caution for several reasons. Several elements selected for review were difficult to assess because there was insufficient information available on the site to make a determination. Because most of the Web sites examined change their content on at least a daily basis and many serve their pages dynamically, the information in this table is only a snapshot in time (September through December 2000) and may not be current. Some users may also have experiences that differ from those described. In addition, the evolving nature of the eHealth industry results in frequent changes in the focus, business practices, and content of the sites mentioned. In fact, some companies merged or were acquired during the preparation of this report. Health content that is integrated within a larger site (e.g., Yahoo!, Excite, Lycos) is not included (except for AOL) in this table because separate data on their health components are not available.

RANK	NAME	UNIQUE USERS/MONTH (THOUS.) [1]	TARGET AUDIENCE [2]	TYPE OF SITE [3]	NEWS AND INFORMATION [4]	RISK ASSESSMENT TOOLS [4]	PROVIDER/ FACILITY DATABASE [4]	CHATS AND BULLETIN BOARDS [4]	ASK THE EXPERT [4]	PROFESSIONAL CONTINUING ED. [4]	ELECTRONIC HEALTH RECORD [4]	SHOPPING [4]
1	Onhealth.com (Merged with WebMD in 2000)	7,973 (Combined with WedMD)	General consumers (71% female, mean age is 38, 81% college grads., 68K mean annual household income)	Portal	•	•	٠	•	•			•
1	WebMD.com (Acquired onhealth.com)	7,973	General consumers, physicians, nurses (pending), health educators, office managers	Portal	•	•	•	•	•	•	•	•
2	Planetrx.com (going out of business in 2001)	2,512	Consumers searching for health products	Segmented	•	•		•	•			•

RANK	NAME	UNIQUE USERS/MONTH (THOUS.) [1]	TARGET AUDIENCE [2]	TYPE OF SITE [3]	NEWS AND INFORMATION [4]	RISK ASSESSMENT TOOLS [4] PROVIDER/ FACILITY DATABASE [4]	CHATS AND BULLETIN BOARDS [4]	ASK THE EXPERT [4]	PROFESSIONAL CONTINUING ED. [4] ELECTRONIC HEALTH RECORD [4]	SHOPPING [4]
3	Ediets.com	2,327	Consumers with interest in dieting and nutrition	Segmented	•		•	•		•
4	Drkoop.com	2,126	General consumers	Portal		• •	•	•		•
5	Drugstore.com	1,996	Consumers searching for health products	Segmented	•			•		•
6	Allhealth.com	1,912	Emphasis on women (for other iVillage sites: 80% female, avg. age = 35, avg. income = 62K, 88% college or better)	Portal	•	• •	•	•	•	•
7	Intelihealth.com	1,854	General consumers (Link w/ health care professional site)	Portal	•	• •	•	•		•
8	NIH.gov	1,766	Health professionals, researchers, general consumer	Segmented	٠					
9	Healthandage.com	1,476	Seniors and geriatrics providers	Segmented	•	•	•	•	•	٠
10	More.com (acquired by Healthcentral.com, currently WebRX.com)	1,249	Consumers searching for health products	Segmented	•	•		•		•
11	Thriveonline.com	1,143	General consumers with emphasis on women and wellness	Portal	•	•	•	•	•	•
12	Healthallies.com	1,036	Consumers searching for medical services	Segmented	•	•				
13	Discoveryhealth.com	1,031	General consumers	Portal	٠	• •	٠	٠		•

RANK	NAME	UNIQUE USERS/MONTH (THOUS.) [1]	TARGET AUDIENCE [2]	TYPE OF SITE [3]	NEWS AND INFORMATION [4]	RISK ASSESSMENT ASSESSMENT TOOLS [4] PROVIDER/ FACILITY DATABASE [4]	CHATS AND BULLETIN BOARDS [4]	ASK THE EXPERT [4]	PROFESSIONAL CONTINUING ED. [4] ELECTRONIC HEALTH RECORD [4]	SHOPPING [4]
14	Asimba.com	951	Consumers with interest in fitness and nutrition	Segmented	•		٠	•		•
15	Healthcentral.com	836	General consumers	Portal	•	• •	٠	٠		•
16	Diabetes.org	787	Consumers and providers with interest in diabetes	Segmented	•	•			•	•
17	Imodium.com	784	Diarrhea medication promotion	Segmented	•			•		•
18	Cvs.com	756	Consumers searching for health products	Segmented	•	•		•		•
19	Drugemporium.com (acquired by Healthcentral.com in 2000, currentlywebrx.com)	745	Consumers searching for health products	Segmented	•	•		•		•
20	Medicinenet.com	712	General consumers	Portal	•					
21	Mayohealth.org	707	General consumers	Portal	•	٠		٠		
22	Medscape.com	702	Health care professionals and students	Portal	•	•			• •	•
23	Mothernature.com (Going out of business in 2001)	662	Consumers with interest in complementary or holistic health/medicine	Segmented	•	•		•		•
24	Healthscout.com	658	General consumers	Portal						
25	Prevention.com	637	General consumers, esp. women	Portal	•	•		•	•	
?	AOL.com (health Web Center)	Not available	General consumers (61% female, 32% college or above, med. Income \$70K)	Portal	٠	• •	٠	•		٠

NAME	OTHER TOOLS AND FEATURES [4]	BANS ATF ADS [5]	SEPARATION OF ADS FROM CONTENT [6]	COLLECTS PERSONAL DATA [7]	COMPREHENSIVE PRIVACY POLICY [8]	EMPLOYS USER TRACKING SERVICE [9]	SECURE SERVER/ ENCRYPTION [10]	
Onhealth.com	Drug database, fee-based advice nurse, symptom checker, online polls		Distinct, no label	•	٠	٠	•	
Webmd.com	Benefits administration, various business tools for providers, eligibility and lab data support, lesson plans for teachers, local content for some cities	•	Distinct, labeled	•	•	•	•	
PlanetRX.com	Drug database		Distinct, no label	٠	٠		٠	
Ediets.com	Personalized coaching tools		Distinct, no label	•	٠	•		
Drkoop.com	Drug database, online polls	•	Distinct, not labeled	•	٠	•	•	
Drugstore.com	Drug database		No ads	٠	(LIM	ITED)	٠	
Allhealth.com	Elder care locator, virtual simulation of checkups		Distinct, not labeled	•	• (LIM	ITED)		
Intelihealth.com	Drug database	•	Distinct, labeled	•	(LIM	ITED)		
NIH.gov	Has information in Spanish	NA	No ads		٠			
Healthandage.com	Interactive simulations for providers		No ads	•	•			
More.com	Child and elder care locator		No ads	•	٠	٠	•	
Thriveonline.com	Drug database, advocacy tools for health issues		Distinct, not labeled	•	•		•	120

NAME	OTHER TOOLS AND FEATURES [4]	BANS ATF ADS [5]	SEPARATION OF ADS FROM CONTENT [6]	COLLECTS PERSONAL DATA [7]	COMPREHENSIVE PRIVACY POLICY [8]	EMPLOYS USER TRACKING SERVICE [9]	SECURE SERVER/ ENCRYPTION [10]	
Healthallies.com	Online marketplace		No ads	•	•		•	
Discoveryhealth.com		•	Distinct, labeled	•	٠		•	
Asimba.com			Distinct, not labeled	٠	•	٠		
Healthcentral.com			Distinct, labeled	٠	٠	٠	•	
Diabetes.org	Online fundraising		No ads					
Imodium.com			NA	•	٠			
Cvs.com	Drug interaction tool		Distinct, not labeled				•	
Drugemporium.com			No ads	•	•		•	
Medicinenet.com			Distinct, labeled	٠	٠	٠		
Mayohealth.org	Drug database	Also no ads on insurance, vitamins, weight loss products, or professional medical products	Distinct, labeled	•	•			
Medscape.com	Sponsors own online journals, practice management tools, online polls		Distinct, not labeled	•	•		•	
Mothernature.com			No ads		٠		•	_
Healthscout.com			Distinct, not labeled		٠	•		
Prevention.com	Online polls		Distinct, not labeled	•	٠			_
AOL.com (health Web Center)			Distinct, not labeled	•	•		•	121

NAME	SUBSCRIBES TO CODES OR AUDIT ORGANIZATIONS [11]	DISCLAIMERS AND WARNINGS [12]	Content IS Peer- Reviewed [13]	EXTERNAL EDITORIAL/ADVISORY BOARD [14]	TEXT EQUIVALENTS [15]	LOADING SPEED (TIME IN SEC.) [16]
Onhealth.com	H, HON	(LIMITEI	D) (DETAILED EDITORIAL	POLICY)	•	Fair (27)
WebMD.com	H, TRUSTe, HON	٠	(DETAILED EDITORIAL	POLICY)		Good (19)
Planetrx.com	TRUSTe, National Assoc. of Boards of Pharmacy	•		٠	•	Poor (42)
Ediets.com	HON	٠				Poor (52)
Drkoop.com	H, HON	(LIMITEI	))		•	Fair (27)
Drugstore.com	TRUSTe, National Assoc. of Boards of Pharmacy, BBBOnline	٠			٠	Poor (62)
Allhealth.com	H, HON	•				Poor (61)
Intelihealth.com	H, HON				•	Fair (27)
NIH.gov		۲	٠		•	Fair (26)
Healthandage.com	HON, TRUSTe		•	•	•	Good (20)
More.com	TRUSTe, HON	٠		•	•	Excellent (3)
Thriveonline.com		٠			•	Poor (36)
Healthallies.com	TRUSTe					Fair (24)
Discoveryhealth.com	H, HON	٠	٠		•	Poor (31)
Asimba.com		٠				Excellent (2)
Healthcentral.com	H, TRUSTe, HON	•			•	Poor (61)
Diabetes.org					•	Poor (33)
Imodium.com						Poor (47)

NAME	SUBSCRIBES TO CODES OR AUDIT ORGANIZATIONS [11]	DISCLAIMERS AND WARNINGS [12]	CONTENT IS PEER- REVIEWED [13]	EXTERNAL EDITORAL/ADVISORY BOARD [14]	TEXT EQUIVALENTS [15]	LOADING SPEED (TIME IN SEC.) [16]
Cvs.com	TRUSTe, NationalAssoc. of Boards of Pharmacy	•			•	Excellent (5)
Drugemporium.com	TRUSTe, HON					Excellent (3)
Medicinenet.com	TRUSTe	٠	٠		٠	Excellent (2)
Mayohealth.org	HON	٠	(DETAILED EDITORIAI	) LPOLICY)	٠	Fair (25)
Medscape.com	Н	٠	•	٠		Poor (71)
Mothernature.com	TRUSTe, BBBOnline	٠			٠	Good (17)
Healthscout.com						Poor (44)
Prevention.com	TRUSTe				٠	Poor (43)
AOL.com (health Web Center)	TRUSTe	•				Fair (29)

NAME	ADS [18]	B2C [19]	<b>B2B</b> [20]	MERGER & ACQUISITION ACTIVITY [21]	LINKS TO OFFLINE MEDIA [22]	OTHER COMMENTS
Onhealth.com	•	•		Recently acquired by WebMD		
WebMD.com	•	•	•	Recent merger with Healtheon, CareInsite, OnHealth.com, Medical Manager Corp.	Link to WebMD TV	
Planetrx.com	٠	•		Going out of business in 2001		
Ediets.com	•	٠				Subscription business model
Drkoop.com	٠	•				
Drugstore.com		٠				
Allhealth.com	•	٠				Part of iVillage
Intelihealth.com	٠	•	•			Interactive tools tend to be more entertaining than those in other sites, sells content to other sites
NIH.gov	NA	NA	NA			Government site
Healthandage.com		٠				
More.com		•		Acquired by Heathcentral.com		Focused on e-commerce, content promotes own products, owns greentree.com
Thriveonline.com	•	٠			Link to Oxygen TV	Part of Oxygen Media
Healthallies.com		•	•			Healthcare marketplace connects cash-pay patients with medical providers

NAME	ADS [18]	B2C [19]	<b>B2B</b> [20]	MERGER & ACQUISITION ACTIVITY [21]	LINKS TO OFFLINE MEDIA [22]	OTHER COMMENTS
Discoveryhealth.com	•	•		Link to Discovery Health TV, link to other Discovery Web sites		Interactive tools tend to be more entertaining than those in other sites, content from Healthscout and Intelihealth
Asimba.com	٠	٠				
Healthcentral.com	•	•	•	Acquired vitamins.com, more.com, drugemporium.com		
Diabetes.org						Nonprofit site, online advocacy
Imodium.com						
Cvs.com		•				
Drugemporium.com		•		Acquired by Healthcentral.com		
Medicinenet.com	•	•				
Mayohealth.org	•					Nonprofit site
Medscape.com	•	•	•	Merged with MedicaLogic		Has affiliated site for consumers, CBS Healthwatch
Mothernature.com		•		Going out of business in 2001		Focused on e-commerce
Healthscout.com	٠	•	•		Owned by Remedy Magazine	Rates other health sites
Prevention.com	•	•				Part of women.com
AOL.com (health Web Center)	٠	•	•	Merged with Time Warner	Time Warner media channels	Web version is a compilation of other eHealth sites

# Comparative summary of most popular eHealth sites

[1] Audience reach in terms of number of unique users per month. Rankings were based on monthly user panel data from PC Data's "Health Care" and "Health & Family" categories for September 2000 (PC Data Online, www.pcdata.com).

[2] Primary target audience and demographics if available.

[3] Type of site: portal (comprehensive coverage of many health issues) or segmented (specializes in specific health issues or focuses on a specific audience segment).

[4] Type of content or features offered: news and information, risk assessment tools, healthcare provider/facility database, chats and bulletin boards, ask the expert, professional continuing education, electronic health record, shopping, other tools and features. This is not a complete inventory of all the features available on the site.

[5] Site has stated policy banning the acceptance of advertising or sponsorship by alcohol, tobacco, or firearm companies. A few sites also ban ads from pornography companies.

[6] Identity of advertisements and sponsored content from regular content: Distinct, no label (advertisements or sponsored content are featured in defined banners, frames, etc. that is visually offset from regular content); Distinct, labeled (advertisements or sponsored content are visually offset from regular content and is clearly labeled as such with accompanying text); No ads. (site does not have advertising from other companies).

[7] Collects personal or sensitive information from users, which may include name, physical or email addresses, SSN, demographics, health status, etc.

[8] Has a comprehensive privacy and confidentiality policy that discloses how personal data is collected, stored, and used.

[9] Uses third party ad network services (e.g., DoubleClick) to track the usage patterns of users across Web sites. Because such use is often not disclosed, absence of a checkmark does not necessarily mean that the site does not use such services.

[10] Employs a secure server and encryption procedures to transmit sensitive information.

[11] Subscribes to voluntary codes of conduct or independent entities that audit for privacy and business practices. These include: H (Health Internet Ethics standards (www.hiethics.com) developed by a coalition of industry eHealth sites that address privacy protections, QA, disclosure, and other issues,); HON (Code of conduct developed by the nonprofit Health on the Net Foundation to help standardize the reliability of health sites (www.hon.ch/HONcode/); TRUSTe (Licensee of the TRUSTe Privacy Program, which is awarded to sites that adhere to established privacy principles and agree to comply with ongoing TRUSTe oversight and consumer resolution procedures, see www.truste.org); BBBOnline (Better Business Bureau Online, has two types of seals and monitors compliance with business practices, one seal is used to indicate site reliability and one is used for privacy assurance, www.bbbonline.org).

[12] Includes appropriate disclaimers and warnings regarding the appropriate use of health sites (e.g., the Internet is not a substitute for appropriate health care consultation).

[13] Has an editorial policy stating that content is peer-reviewed.

[14] Has established an external editorial or advisory board (besides the Board of Directors of the company). However, in almost all cases, exactly how the editorial or advisory board provides oversight to the day-to-day editorial process is not clear.

[15] Text equivalents describe the function or purpose of content for non-textual information (images, applets, sounds, etc.). This allows information conveyed by graphics to be accessed by screen readers, non-visual browsers, and Braille readers. This is part of the consensus guidelines enhancing the accessibility of sites for disabled persons and other groups drafted by the Web Accessibility Initiative of the World Wide Web Consortium (www.w3.org).

[16] Load time refers to the average time (seconds) it takes to view the top-level page using a 28.8Kbps modem. Tested using Netscape's Web Site Garage tool at http://websitegarage.netscape.com/.

- [17] The site's business model includes advertising.
- [18] The site's business model includes business-to-consumer transactions (e.g., retail e-commerce).
- [19] The site's business model includes business-to-business transactions (e.g., sales and services to other companies).
- [20] Recent and pending merger and acquisition activity.
- [22] Owns offline media channels, such as broadcast television or radio or print media to complement online activities.



#### **Table of Contents**

**Foreword** 

**Preface** 

**Acknowledgements** 

#### **Executive Summary**

**Introduction** 

Current Status of the eHealth Sector

Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

APPENDIX 1 - eHealth-related information resources.
APPENDIX 2 - Comparative Summary of Most Popular eHealth Sites.
APPENDIX 3 - Foundations with explicit interest in information and communication
technology issues.
<b>APPENDIX 4</b> - Venture capital funds with a specific interest in eHealth-related
investments.
<b>APPENDIX 5</b> - Non-profit organizations with major eHealth-related activities.

# **APPENDIX 3** Foundations with explicit interest in information and communication technology issues.

The following are examples of foundations that have an explicit interest in funding projects related information and communication technology according to published materials. Many of these, especially the corporate foundations, are specifically focused on the use of emerging technologies to improve education, but some also have an interest in eHealth areas. The descriptions of the following foundations are verbatim or slightly edited versions of text from their Web sites or the Foundation Center Web site (www.fdncenter.org).

**Independent Foundations** 

#### Alfred P. Sloan Foundation (www.sloan.org)

The Sloan Foundation has several initiatives to promote science and technology education. The Goal of their Public Understanding of Science and Technology program is to "enhance people's lives by providing a better understanding of the increasingly scientific and technological environment in which we live." Their Learning Outside the Classroom initiative seeks to "make higher education and training anytime and anywhere for anyone who is motivated to seek it." Grants have gone to institutions of higher education to encourage their use of Asynchronous Learning Networks, which make possible access to remote learning resources such as instructors, fellow students, text, and software.

# Benton Foundation (www.benton.org)

The Benton Foundation seeks to "shape the emerging communications environment in the public interest... Benton initiates projects in three interdependent areas: 1.Defining and promoting public policies that support the public interest services and capacities of new media; 2. Helping nonprofit organizations use communications tools and strategies to be information providers and social advocates; and 3.Creating knowledge centers in the new media that are trusted sources and guides to nonprofit information and action."

## Bill & Melinda Gates Foundation (www.gatesfoundation.org)

The Foundation is "dedicated to sharing the promise of new technologies with all citizens." It has three focus areas: Education, Libraries, and Public Access to Information. These programs seek to improve teaching and learning, enhance access to technology through libraries, and increase access points to the Internet and resources for computerbased solutions.

# California Healthcare Foundation (www.chcf.org)

The Foundation has several focuses including managed care, the uninsured, health policy and regulation, health care quality, and public health. "Grants focus on areas where the Foundation's resources can initiate meaningful policy recommendations, innovative research, and the development of model programs." The foundation has sponsored several analyses of privacy issues related to health Web sites, a series of reports on the future of eHealth, and an "eHealth Reports" feature on their Web site.

## California Wellness Foundation (www.tcwf.org)

The California Wellness Foundation seeks to "improve the health and well-being of the people of California through health promotion and disease prevention programs." The Foundation concentrates its grantmaking activities in five areas: community health, population health improvement, teenage pregnancy prevention, violence prevention, and work and health. They have funded IT-related projects.

## Canyon Research (www.canyonresearch.org)

This San Diego-based foundation "supports research and education projects that focus on innovative computer-related communications technology, public communications policy, and domestic communications regulatory issues. The Foundation seeks to advance communications research and education."

## Case Foundation (no Web site)

Established by A O L chief executive Steve Case and his wife, Jean. Provided \$10 million to start up PowerUp, which is a partnership of more than a dozen nonprofit organizations, major corporations and federal agencies, to give underserved children access to technology and guidance on how to use it. It is focused on schools and community centers.

## Community Technology Foundation of California (www.zerodivide.org)

Founded in 1998 by 134 community organizations and Pacific Bell (now part of SBC Communications), this community foundation "works to meet the needs of

California's underserved communities for full and equal access to basic and advanced telecommunications services, and their needs for knowledge carried by these services."

## J.C. Downing Foundation (www.jcdowning.org)

The San Diego-based J.C. Downing Foundation supports efforts and projects in five program areas: Education and Human Development, Environmental Research and Preservation, Fine Arts, Sports and Athletics, and Technology and Communication.

#### John and Mary R. Markle Foundation (www.markle.org)

The Foundation "promotes the development of communications industries that address public needs." Most of the Foundation's current work is through following programs: Public Engagement through Interactive Technologies, Policy for a Networked Society, Interactive Media for Children, and Information Technologies for Better Health.

## Kellogg Foundation (www.wkkf.org)

The Kellogg Foundation seeks to "increase and ensure equal access to information and electronic media. This includes support for professions education and policy issues surrounding intellectual property rights and privacy. Priorities include building the human capacity to strengthen community on-line communication systems in health, education, rural development, and the non-profit sector. Special attention will be focused on disenfranchised populations, especially among the young."

## Nathan Cummings Foundation (www.ncf.org)

The Foundation's Health Program is committed "to improving the quality of life at its beginning and at its end by supporting humane patient-centered care that provides comfort and caring, as well as cure. The Foundation is concerned about patient/provider communication, patient empowerment, and the importance of family and community in nurturing new life and in facing death." The foundation was instrumental in raising the salience of Y2K readiness to health care institutions.

## Paul G. Allen Virtual Education Foundation (www.paulallen.com/foundations/)

The Bellevue, Washington-based foundation seeks "to advance the development and growth of online learning especially distance learning that eliminates dependence upon face-to-face contact as the primary context for learning. The foundation primarily funds projects to produce digital content for education, including, but not limited to, multimedia instructional materials and instructional software. Grants support the design, testing and production of digital materials. The foundation also supports projects focused on the evaluation of online education in practice."

## Waitt Family Foundation (www.waittfoundation.org)

The Waitt Family Foundation, created by the founder of Gateway Computer Company, is "dedicated to eliminating the wide gulf between those who have Internet access and those who do not by providing quality learning experiences through the PowerUp program and online resources." It is providing up to 50,000 computers and Internet appliances for the next three years to PowerUP. The Waitt Family Foundation Technology Resource Center was established "to research and develop programs that will provide communities with the ability to participate in today's information-driven society."

## **Corporate Foundations**

# ADC Foundation (www.adc.com/main\_template/1,1034,25,00.html?contcat=0)

This foundation seeks to support innovative educational programs and organizations that "prove the future of society by supporting excellence in science and technology education" and "expand telecommunications access for the disadvantaged."

## AOL Time Warner Foundation (www.aoltimewarnerfoundation.org)

The AOL Time Warner Foundations' mission is "to use online technology to benefit society, improve the lives of families and children, and empower the disadvantaged." They focus their giving in five core areas: the Digital Divide, Civic Engagement, Kids/Family/Education, Philanthropy, and Healthcare. Its health care initiative seeks to "improve access to and make health information and services more widely available... especially to senior citizens – and build interest and capacity among healthcare providers to use the medium."

# AT&T Foundation (www.att.com/foundation/index.html)

The foundation invests in three areas: Education, Civic & Community Service, and Arts & Culture. "Bringing the benefits of technology and employee engagement to the customer and the local communities where we have a presence is what we're all about... many of the programs we fund are tied to inventive uses of technology and the spirit of volunteerism."

## BellSouth Foundation (www.bellsouthcorp.com/bsf/index.html)

The BellSouth Foundation seeks to improve outcomes and stimulate active learning for students in elementary and secondary education in Alabama, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee. The foundation has awarded numerous grants related to use of technology in education. It also sponsors a health and education initiative.

Compaq Computer Corporation (www5.compaq.com/corporate/community/index.html)

Compaq "provides technology, product and cash contributions, and encourages employee involvement in programs that align with the theme: Investments and Innovations through Technology...Enhancing Education and Strengthening Communities... we can help schools and organizations realize the full potential of technology as a tool to enhance their programs and business operations."

# Digital Blackboard Foundation (formerly Washington Software Foundation) (<u>www.wsf-wa.org/about/</u>)

The foundation supports "revolutionary teachers who open opportunities for students and close the education gap in schools and communities at risk. We incorporate classroom technology into new educational practices, leveraging what works in the classroom to help these teachers improve kids' performance."

## eBay Foundation

## (www.pages.ebay.com/community/aboutebay/foundation/history.html)

Established in June 1998, the eBay Foundation's primary focus has been to support organizations that provide hope, tools and direction to assist people in reaching their full potential through the creative application of technology.

## Intel Corporation & Foundation (www.intel.com/intel/community/index.htm)

The focus of Intel's giving and outreach programs is on bettering education, supporting Intel communities, improving life with technology, and protecting the environment. The Intel Foundation funds programs which "advance math, science and engineering education, promote women and under-represented minorities entering science and engineering careers, and increase public understanding of technology and its impact on contemporary life."

# MCI Worldcom (www.wcom.com/marcopolo/)

Along with six national nonprofit organizations, MCI Worldcom has sponsored the MarcoPolo program that "provides no-cost, standards-based Internet content for the K-12 teacher and classroom, developed by the nation's content experts. Online resources include panel-reviewed links to top sites in many disciplines, professionally developed lesson plans, classroom activities, materials to help with daily classroom planning, and powerful search engines."

## Microsoft Corporation (www.microsoft.com/giving/default.htm)

The Microsoft Corporation makes grants of cash, software, and technical support to nonprofit organizations worldwide "to help bring the benefits of information technology to people and communities."

## NEC Foundation of America (www.nec.com/company/foundation/)

The NEC Foundation of America "makes cash grants to nonprofit organizations and programs with national reach and impact in one or both of the following arenas: science and technology education, principally at the secondary level, and/or the application of technology to assist people with disabilities."

#### Oracle Corporation (www.oracle.com/corporate/giving/community/index.html)

The Oracle Corporation contributes funds directly to environmental protection; endangered animal protection; medical research; and K-12 math, science, and technology educational programs.

## Pacific Bell Foundation (www.pacbell.com/About/NewsCenter/0,1119,,00.html)

The Pacific Bell Foundation is dedicated to "preparing people from all cultures to participate in the economic, social and civil life of their communities by improving the quality of public education, providing access to technology, and building the capacity of community-based organizations" in California and Nevada. It has supported initiatives on the digital divide and other technology issues.

# Verizon Foundation (formerly Bell Atlantic Foundation) (foundation.verizon.com/)

The foundation focuses on the following areas: Literacy, Digital Divide, Workforce Development, Community Technology Development, and Employee Volunteerism.

## Foundations with Interest in International Technology Issues

## Engineering Information Foundation (www.eifgrants.org/index.html)

The foundation's mission is "to improve worldwide engineering education and practice through information technology and the recruitment of women." They support " developmental projects, instructional projects, and training programs in engineering education and research... these currently include the availability and use of published information, women in engineering, and information access in developing countries."

## Ford Foundation (www.fordfound.org)

Cosponsors the Project for Information Access and Connectivity, Wired for Information in Africa with the Rockefeller Foundation.

# Mitchell Kapor Foundation (www.mkf.org)

The founder of Lotus Development Corporation created this California-based foundation. Their Program on the Impact of Information Technology is "focused on the ways in which the Internet and other contemporary computing and communications technologies are transforming the social, cultural, and economic landscape, e.g. the effects of economic globalization enabled by the Internet and the creation of a "digital divide". Areas of interest include the impact of information technology on economic and social equity; community; the workplace; privacy and identity; and health and the environment."

## Rockefeller Foundation (www.rockfound.org)

The Foundation's Communication For Social Change program "will foster the most effective, innovative practices of communication for development in the public and nonprofit arenas to accelerate the pace of positive change for people who are poor and excluded. The program will build processes to ensure that communication planning is essential to all Foundation program work, test methods to train grantees working with poor people to advance communication for social change, and develop evaluation and measurement methods to quantify the effectiveness of our work."

## Soros Foundation (www.soros.org/internet/index.html)

Within the Soros Foundations Network, many of the programs focus on Central and Eastern Europe and the former Soviet Union. The foundation has funded grants related to e-mail connectivity; infrastructure and connectivity in Central and Eastern Europe; and Internet policy work. "In 2000, the program was overhauled to reflect the evolution of the Internet and changes on the ground. The program now concentrates on organizational capacity building and Internet policy work and has a primary focus in the areas of independent media, human rights and Internet policy."



Table of Contents	APPENDIX 1 - eHealth-related information resources.
Foreword	APPENDIX 2 - Comparative Summary of Most Popular eHealth Sites. APPENDIX 3 - Foundations with explicit interest in information and communication technology issues.
Preface	APPENDIX 4 - Venture capital funds with a specific interest in eHealth-related investments.
Acknowledgements	<b>APPENDIX 5</b> - Non-profit organizations with major eHealth-related activities.
Executive Summary	
Introduction	<b>APPENDIX 4</b> Venture capital funds with a specific interest in eHealth- related investments.
Current Status of the eHealth Sector	The following are examples of major venture capital funds that invest in eHealth- related companies. Many directories of financing options for start-up companies
Perspectives of Major	are available (e.g., <u>www.businessfinance.com</u> , <u>www.cfol.com</u> ,
eHealth Stakeholders	www.internetvcwatch.com, www.ipo.com).
Overview of Major eHealth Issues	Alloy Ventures ( <u>www.alloyventures.com</u> )
A Cautionary	Cardinal Partners (www.cardinalpartners.com)
View of eHealth	Euclid Partners (www.euclidpartners.com)
Internet-Related Trends and Their Implications	Frazier Healthcare ( <u>www.frazierco.com</u> )
Key Questions	Internet Healthcare Group ( <u>www.ihcg.com</u> )
for eHealth	InterWest Partners ( <u>www.interwest.com</u> )
<u>References</u>	Mayfield Fund (www.mayfield.com)
<u>Appendices</u>	Mediphase Venture Partners (www.mediphaseventure.com)
	MedVenture Associates ( <u>www.medven.com</u> )

Merck Capital Ventures (no Web site)

Salix Ventures (<u>www.salixventures.com</u>)



#### **Table of Contents**

**Foreword** 

**Preface** 

**Acknowledgements** 

#### **Executive Summary**

**Introduction** 

Current Status of the eHealth Sector

Perspectives of Major eHealth Stakeholders

Overview of Major eHealth Issues

A Cautionary View of eHealth

Internet-Related Trends and Their Implications

Key Questions for eHealth

**References** 

**Appendices** 

APPENDIX 1 - eHealth-related information resources.
APPENDIX 2 - Comparative Summary of Most Popular eHealth Sites.
APPENDIX 3 - Foundations with explicit interest in information and communication technology issues.
APPENDIX 4 - Venture capital funds with a specific interest in eHealth-related investments.
APPENDIX 5 - Non-profit organizations with major eHealth-related activities.

# **APPENDIX 5** Nonprofit organizations with major eHealth-related activities.

The following are examples of non-profit organizations that have major eHealthrelated activities according to published materials. The following descriptions are verbatim or slightly edited versions of text from their Web sites.

#### Alliance of Medical Internet Professionals (www.amip.org)

A new member organization formed to "connect Medical Internet Professionals world-wide, to improve the quality of healthcare to people around the globe, and to discover innovative methods for employing Internet technology in the practice of medicine."

#### American Medical Informatics Association (www.amia.org)

A major, longstanding membership organization "dedicated to the development and application of medical informatics in the support of patient care, teaching, research, and health care administration. Members include physicians, nurses, educators, computer and information scientists, biomedical engineers, medical librarians, and academic researchers."

## British Healthcare Internet Association (www.BHIA.org)

An individual membership association based in Great Britain that "promotes the advancement of healthcare through the application of Internet technologies and the Bill of Rights of the Internet."

#### California Telehealth & Telemedicine Center (www.telehealth.calhealth.org)

The mission of the organization is to "promote the use of new information and communication technologies as tools to improve and expand access to health services and information in California's medically underserved communities." Provides grants to community eHealth technology projects.

#### Center for Technology and Democracy (www.cdt.org)

A nonprofit organization that seeks to "conceptualize, develop, and implement public policies to preserve and enhance free expression, privacy, open access, and other democratic values in new communications media." Has sponsored reports on online privacy and content issues.

#### Digital Divide Network (www.digitaldividenetwork.org)

The organization "facilitates the sharing of ideas, information and creative solutions among industry partners, private foundations, nonprofit organizations and governments interested in the digital divide issues."

#### Digital Partners (www.digitaldivide.org)

A nonprofit institute that seeks to "catalyze investments in technology content and infrastructures needed by the poor, and fosters collaborations between digital entrepreneurs and nonprofit leaders to help the poor achieve self-sufficiency."

#### eHealth Institute (www.ehealthinstitute.org)

A nonprofit organization that seeks to "enhance the capacity of people to access and utilize eHealth resources, improve the state of knowledge and public understanding of eHealth-related issues, and improve the quality and effectiveness of eHealth resources."

#### eHealthcare Association (www.workgroup.org/ethics/ethics\_teha.htm)

This member association represents "healthcare Internet content, connectivity and commerce companies. It provides representation and advocacy, networking and information for its members."

## Health Internet Ethics (Hi-Ethics™) (www.hiethics.org)

An alliance of major eHealth information providers, mostly commercial, formed to develop an ethical code of conduct for developers focusing on content, advertising, privacy issues, and commerce.

#### Health on the Net Foundation (www.hon.ch)

A Swiss nonprofit organization whose mission is to "guide healthcare consumers and providers to sound, reliable medical information and expertise." They established the HON Code of Conduct for health Web sites.

## Health Privacy Project (www.healthprivacy.org)

Based at Georgetown University, it is dedicated to "raising public awareness of the importance of ensuring health privacy in order to improve health care access and quality, both on an individual and a community level." They have authored several reports on online privacy of health information.

#### Internet Health Alliance (www.internethealthalliance.org)

A nonprofit member organization that seeks "to accelerate the adoption of Internet in healthcare by delivering national visibility to the common interests of leaders in the healthcare and technology communities."

#### Internet Healthcare Coalition (www.ihealthcoalition.org)

A nonprofit association representing "a variety of individuals and institutions interested in healthcare on the Internet." They have proposed a voluntary code of ethics for health Web sites, and host an annual meeting.

#### Internet Policy Institute (www.internetpolicy.org)

A nonprofit think-tank focused on the "economic, social, and policy issues related to the global development and use of the Internet." It is funded by a consortium of large IT corporations.

#### Internet Society (www.isoc.org)

A professional membership society with more than 150 organizational and 6,000 individual members in over 100 countries. "It provides leadership in addressing issues that confront the future of the Internet, and is the organization home for the groups responsible for Internet infrastructure standards, including the Internet Engineering Task Force and the Internet Architecture Board."

#### Institute for the Future (www.iftf.org)

A nonprofit research firm "specializing in long-term forecasting, alternative futures scenarios, and the impacts of new products and next-generation technologies on society and business" [and health].

#### Medical Library Association (www.mlanet.org)

A national professional member organization "dedicated to improving the quality and leadership of the health information professional in order to foster the art and science of health information services." Has posted reviews of eHealth sites.

#### Microsoft Healthcare Users Group (www.mshug.org/about/index.asp)

An independent, nonprofit organization that serves "the needs of information systems developers and users in the healthcare industry. It is funded by individual and corporate membership dues and is not affiliated with Microsoft Corporation."

# World Wide Web Consortium (W3C) (www.w3.org)

Founded by Tim Berners-Lee, inventor of the Web. The Consortium develops "interoperable technologies (specifications, guidelines, software, and tools) to enhance use of the Web for information, commerce, communication, and collective understanding. It has developed more than 20 technical specifications for the Web's infrastructure."



Route 1 and College Road East Post Office Box 2316 Princeton, New Jersey 08543-2316 www.rwjf.org

ISBN 0-942054-14-8