PARTNERSHIPS FOR NETWORKED HEALTH INFORMATION FOR THE PUBLIC

Rancho Mirage, California
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SUMMARY CONFERENCE REPORT

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INTRODUCTION

Electronic consumer health information is at the intersection of many dynamic developments. The concept of health is broadening to include wellness, prevention, and the effects of the environment. The trends in health care are moving away from hospitals toward ambulatory, home-, or community-based care. Commercial and free networks are being created at the national, State, and local levels, and it's being discovered that health information is a popular service for these networks. Traditional health information providers are perceiving that new media offer intriguing opportunities for reaching audiences. It is being demonstrated that health care cost containment and market opportunities offer economic incentives.

These trends have many implications. There is increased responsibility on individuals to take better care of themselves and their families and to make a range of decisions about medical care. Prevention, patient education, and the management of health and disease require an information infrastructure that links homes, hospitals, clinics, schools, worksites, and community settings. And perhaps most important, there are a wide range of players and tantalizing prospects for new partnerships among them.

The first conference on Partnerships for Networked Health Information for the Public, held in Rancho Mirage, California, in May 1995, started the process of identifying parties who have an interest in this subject. In addition to the more obvious partners—government and the health care sector—it brought together voluntary organizations that provide information and services in specific fields; community-based organizations that provide local access to information; public and medical libraries that serve the well and the ill, families, and caregivers; employers, insurers, and other organizations that promote wellness and wise medical consumerism; and electronic publishers, interactive applications developers, and telecommunications and computer companies that can create or deliver vital health information. The diversity of the presentations and participants revealed, or suggested, fruitful linkages across an array of boundaries.

We all share the goal of HEALTHY PEOPLE 2000: to increase the span of healthy life for all Americans. We are also united in our concerns about equitable access to health services and cost containment. Networked health information can help more people achieve their optimum health or confront disease and disability with greater confidence. Individually and collectively, our lives can be enhanced through health knowledge.

J. Michael McGinnis, M.D.

Scholar in Residence, National Academy of Sciences;
Former Deputy Assistant Secretary for Health, and
Director of the Office of Disease Prevention
and Health Promotion

SUMMARY OF PLENARY PRESENTATIONS

Introductory Remarks

C. Everett Koop, M.D., Sc.D., Senior scholar, C
Everett Koop Institute, Dartmouth Medical School

While the private sector built the railroads and the
government built the highway system, the informa-
tion infrastructure is too important to leave to either
alone. Laws and regulations must be changed to
permit full and efficient development. Private lead-
ership must have a national vision. The telecommu-
nications revolution will help serve a health care sys-
tem that is being dramatically changed by the pri-
vate sector as well as meet medical education needs,
which now include lifelong learning. Creating a
health information infrastructure will be costly, but
the biggest barriers are laws and attitudes. Partner-
ships at the highest level must reach to the local
level, bringing health information to people right in
their homes.

Keynote Address

Reed Tuckson, M.D., President, Charles R. Drew
University of Medicine and Science

Today's challenge is the careful coordination of de-
centralizing changes in health care and information
technology to serve the health of all Americans.
New trends can be seen in the health care industry.
The system has been specialty driven, hospital-
based, and unaffordable and inaccessible to many
people. Now, the disease model that has dominated
medical care is being modified by a recognition of
the complex social and environmental factors that
influence health. Other influences include managed
care, with an emphasis on cost-effectiveness, the
movement toward community- and home-based
care, and the increased role of the patient in navigat-
ing the health care system and making health deci-
sions.

The new technology already brings incredible health
information resources to people in their homes: in-
formed decisions on alcohol treatment, choice of
therapists and other medical services, methods of
interviewing a physician, and informed consent and
patient rights, just to name a few subjects.

These telecommunications developments will dra-
matically change the doctor-patient relationship. Pa-
tients with easy access to health information will
have different presentations to and expectations of
their physicians. Smarter patients may become more
demanding and tailor their own treatment by draw-
ing on many sources. They will go to providers not
for information, but for judgment, wisdom, and ex-
perience. The physician may provide context for pa-
tient-generated data, but the days of giving out a
four-color brochure are over, said Tuckson. The doc-
tor-patient relationship will have to be watched care-
fully over the next few years. Since the quality of in-
formation the patient gathers cannot be monitored,
much provider time might be spent correcting errors
of fact or interpretation.

Questions about issues such as efficiency, cost, and
price abound. For example, how will time associ-
ated with technology-based consultation be compen-
sated? Are such collaborations valuable enough that
plans will provide dedicated funds? Will a new type
of consultative provider evolve? Would it be desir-
able to have online practitioners? Would telecommu-
nications providers give this expertise as part of their
online services? Can these make the process even
more costly, inefficient, and frustrating? And given
the reality of the competitive environment and the
importance of the satisfied patient, will physicians
be forced to change their behavior? Will incentives
be provided for judgment, wisdom, and experience?

Issues of access and equity are important as well.
Questions about who will pay are important for the
poor, who are already shut out of the system. Many
present technologies are not available to many
Americans, and now more services may be available
to still fewer. If the gap is increasing, what can be
done? In the present climate, there may be no com-
passion from those controlling the purse strings. We
are asking the private sector to put poor communi-
ties on the Internet.

Preventable disease and death still afflict many com-
munities. Despite this wonderful technology, on any
given night 100 women will lose a baby in the first
year of its life due to preventable disease, trauma or
accident. And in one year, 70,000 black men die of

preventable diseases. We still have a long way to go. The purpose of this conference should be, above all, to seek ways to use the new tools to assist us in best serving the health of all the people and to do so without adverse consequences to their quality of life.

If we are going to overcome the isolation that the information age presents, we must pay attention to community partnerships and work to create an environment that helps people take advantage of the technology for their best interests. If people are stuck in isolated cubicles staring at screens, how can we build the link between public health and private care? We must follow the admonition of the great cellist Pablo Casals—that man should be purposefully driven by a respect for life and resist distractions from this.

Consumer Health Information Demand and Delivery: A Preliminary Assessment

John Harris, Vice President of Reference Point Foundation, presented the results of a preliminary study of consumer health information that was commissioned for the conference. The last publicly released general study on consumer health information was commissioned by General Mills in 1979. In the 16 years since then, the scope of consumer health information has become wide and diverse. With increased responsibility for health, consumers have developed both broad interests and very specific needs.

Who Is the Consumer?

Surveys show that there is no typical health information consumer. Tendencies can be distinguished across various demographic lines.

- **Age** — As people grow older, health information consumption increases with the use of health care. Older people are generally better informed than younger people and more likely to use multiple sources for information than younger people. Younger people, on the other hand, seem more likely to use new sources for information, such as the Internet and other computer technology.
- **Disability** — The disabled person is much more likely to seek health information; disabled people seem also to be more dissatisfied with consumer information.
- **Gender** — Women tend to be slightly better informed than men; this finding is related to their greater use of health care services. It is also true that women are more likely to be consumers of health information on behalf of other persons.

- **Race and Ethnicity** — Race and ethnicity often appear to be significant variables. This apparent significance is perhaps a consequence of two powerful distortions: the influence of the socioeconomic variables of income and education and the barrier of language for non–English-speaking consumers. Cultural or value-oriented factors are also involved.
- **Socioeconomic Factors** — In every survey or study, income and education significantly affected health and how health information was consumed. People with lower levels of income and education are half as likely to read health-related materials, three times more likely not to seek health information when they have a health problem, and twice as likely to have problems getting the information.

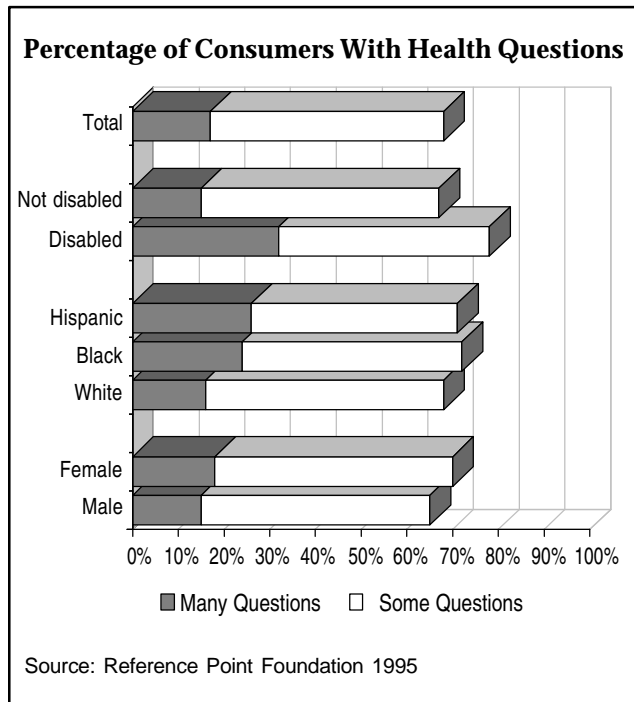### The Definition and Scope of Consumer Health Information

The Consumer Health Information subgroup of the National Information Infrastructure Task Force has defined consumer health information as "any information that enables individuals to understand their health and make health-related decisions for themselves or their families."

An analysis of Medline, the bibliographic database of the National Library of Medicine (NLM) that lists about 8 million books, monographs, and periodicals concerning health and medicine, suggests that health information for consumers can be categorized in a wide variety of interrelated subsets, depending upon the use of that information. "Patient information" is a broad term for information about diseases, medical treatment, or drugs that help the patient cope with an illness and comply with treatment. It is also the information that helps the patient and the family anticipate and understand how the illness may affect the person's health and life generally. Patient information encompasses "medical instructions," meaning physician or medical guidance for treatment, and "decision support," information that describes treatment alternatives and their consequences. The area of "medical records," meaning the records of individual patients, is increasingly considered to be part of consumer health information as well. "Health education" refers to information that seeks to promote wellness by improving awareness, attitudes, skills, and behaviors related to health risks. "Self-care" information covers how to interpret symptoms, care for oneself or family, and find peer support groups. "Health care shopping" information, also called "quality in care information," seeks to help consumers select among plans and providers. The area of "alternative medicine" cuts across all these

areas, as patients and providers explore nontraditional approaches to wellness and disease treatment.

Demand for Consumer Health Information

There is strong interest in health information. Health matters as a subject outrank interests in other public policy issues. However, "active consumption," in which a person seeks information about a health problem, is significantly different from general demand or "questions" about health. There is no variation of this pattern across gender, race, or disability status.

Percentage of Consumers With Health Questions

Source: Reference Point Foundation 1995

Sources of Health Information Cited by Focus Groups

	Black (urban)	Black (rural)	Native American	Hispanic	Senior	Asian American	Chronic Condition	Disabled	Caregiver
church	X	X		X					
clinics	X	X	X	X					
community org.	X	X	X	X	X			X	X
conferences									X
county health cntr.	X								
doctors	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
family/friend	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
government					X				
health fairs			X		X				
herbalist			X			X			X
hospital	X		X	X	X	X		X	X
hotlines							X	X	X
Internet/computers								X	
libraries	X	X	X	X	X	X	X		X
magazines	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
newsletters					X				X
newspapers		X	X		X	X		X	X
nurses	X				X	X	X	X	X
ombudsman									X
pharmacists		X	X		X	X	X	X	X
radio		X	X		X	X		X	X
school	X			X					
television	X	X	X	X	X	X		X	X
voluntary health org.	X				X		X	X	X
Total Sources Cited	**13**	**11**	**13**	**10**	**15**	**11**	**8**	**12**	**17**

Source: Reference Point Foundation 1995

Supply of Consumer Health Information

The supply of print consumer health information is huge and varied. Health information is the single largest subject for popular and professional consumption. However, people's first source of information about specific "health problems" is usually an intermediary such as a professional (nurse, doctor, or librarian) who can help them understand or interpret the information.

When the consumer needs medical treatment for a disease or condition, the first choice and major source of information is the health care provider.

Health care facilities offer health education services, many of which focus on wellness and health promotion.

Other sources of health information include libraries, Federal and private clearinghouses, mass media, Federal programs, employers, community organizations, and Voluntary Health Agencies (VHAs).

VHAs are major providers of information about specific health concerns.
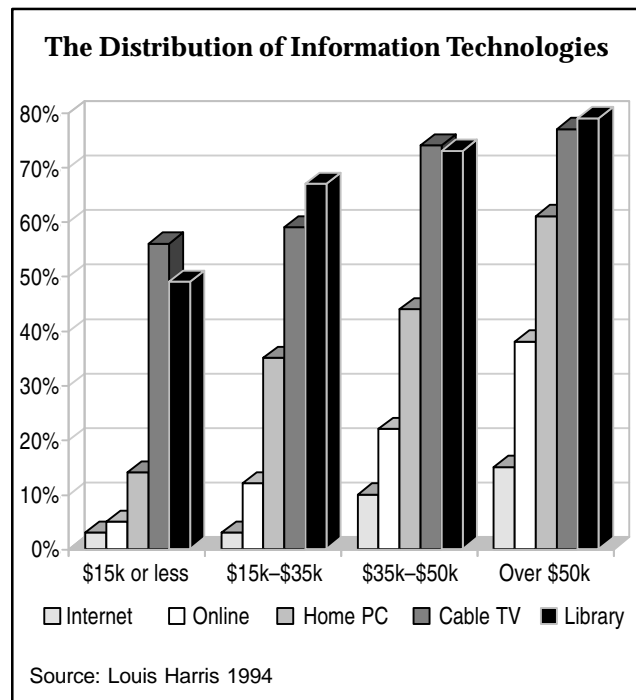
Problems with Health Information

People have many problems with health information, including how to interpret conflicting or differing information, judge reliability, choose from among many alternatives, and deal with frustration in getting information from doctors.

The Potential of Electronic Sources of Health Information

Networked health information can be more timely and complete than any other media. It has the advantage over other publishing technology to facilitate timely delivery and to promote better and wider access to information resources generally. Many managed care and other health related institutions are exploring online health information resources for their members or patients, accessible either within the care setting or in the home.

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But networked information also results in great inequities in its delivery and access. Even with the rapid growth of the number of personal computers in homes, networked health information may further disadvantage those with fewer resources but greater needs.

The Distribution of Information Technologies

Source: Louis Harris 1994

Conclusions

The findings identified a number of key problems or issues that must be addressed to better serve demand and delivery of consumer health information. Currently, there is a lack of clear data with which to assess when, how, and why consumers seek information. Knowledge of the health-related behavioral outcomes of health information consumption related to prevention, self-care, and utilization of health care services is fragmented. Nor is there much data on the relation of consumer health information to patient satisfaction, health outcomes, or cost savings. The research agenda is clearly broad and compelling.

Response Panel

Linda Harris, Ph.D., George Washington University, moderator.

Margaret Cary, M.D., Regional Director of the U.S. Department of Health and Human Services, stressed the importance of maintaining low-tech, high-touch personal consultation, especially for those with lower educations—the "information have-nots."

Robert Harmon, M.D., Medical Director of the MetraHealth Center for Corporate Health, noted that some insurers, especially HMOs, are already providing health information to plan members through print and telephone services. Some are already providing electronic services. More research is needed on the effectiveness of electronic health information—what works? The Federal government, and in some cases the States, should use public services as test beds to study community-based health information sites. The Federal government also has a role in promoting the development of standards. Doctors should be part of partnerships in these areas.

Mary Gardiner Jones, LLD, President of the Alliance for Public Technology, commented on the myth of the "typical consumer," who is often missed in the mass media. The new technology gives people information more relevant to their actual situation, but it may be necessary to move away from the traditional search modality. People don't understand searches; they just have questions they want answered. Because the home is such a center of information access, the government and private industry need to act together to make connectivity to the home a priority. The government also has a special role in the area of quality and integrity of information, at a minimum by providing information resources with a system of disclosure so that patients will find these reliable.

George Needham, Executive Director of the Public Library Association, reflected on calls for a good social interface for the technology. Microsoft Corporation's answer is "Bob," which has a variety of characters to help people navigate and organize information. But the public library is already a good social interface. With over 16,000 branches, public libraries answer up to one million health-related questions each week. To improve this service, training models and promotional activities can be created. But no one institution can handle the overwhelming demand for health information. Libraries can partner with medical professionals and other local institutions.

Gary Schwitzer, Production Director of the Foundation for Informed Medical Decision Making, emphasized the glut of information and the problems with various sources. Doctors, often the first source, have little time to spend with patients. Mass media coverage focuses on the issue of the day. Trying to get health information off the Internet is like drinking from a hose. There is a mountain of both print and electronic health information, but much of it is superficial or even inaccurate. Computer decision-support programs try to give patients unbiased options that can be tailored to their particular situation. They include videotaped patient interviews with people who have faced similar problems so that the individual can vicariously experience the decision process of others. Health care reform begins with this shared patient and provider decisionmaking.

LUNCHEON PRESENTATION:
HEALTH COMMUNICATION AND THE NEW MEDIA

William Smith, Ed.D., Executive Vice President of the Academy for Educational Development talked about the perspective of health communications and social marketing. There are differences among the new media and their ability to reach millions of people without going through peer review, paid (or public service) advertising, or talk shows. But the problem still exists: to help people make better decisions about their health—about prevention, screening, and treatment. With much of poor health and disease avoidable or more manageable through changes in behavior, it's necessary to find out how the new media can impact a range of behaviors.

There are three relevant models of voluntary behavior change: information, marketing, and decision-making/counseling. The information model reflects the basic notion that people don't do things because they don't know enough about them. In this model, people are perceived as students who must study and learn their lessons. Marketing argues that this is insufficient. People need information, but also better services, priced competitively, and easily accessible. Marketing calls for an integrated approach to promote behaviors determined to be in the public's interest. This model sees people as consumers, making choices between competing health behaviors, based on the best deal they get in exchange for their new behavior. Decisionmaking models give people more in-depth information along with skills to find other resources, make comparative judgments, and act as decisionmakers rather than passive consumers. This model perceives people as motivated information managers, adroitly arriving at complex judgments after significant investment of time and energy.

Behind all of these behavioral intervention models is a body of social science that explains why, if not how, these different approaches work. The basic notion is that between risky behavior and effective interventions there are determinants. Three of the most robust and interesting determinants of human behavior are social norms, self-efficacy, and perceived consequences. Social norms suggest that people adopt a new behavior if they feel that the people they most

care about want them to adopt it. Self-efficacy refers to self-confidence related to a specific behavior. It measures whether people feel they are able to perform a specific new behavior without difficulty or embarrassment. Perceived consequences measures whether individuals feel a new behavior has advantages over its existing competition. Of course, definitions of "advantage" vary widely. Empirical investigation of specific individuals and groups is necessary to determine what advantages or consequences matter to them relative to a specific new behavior.

The oversimplified lesson for behavior change is that the new behavior must be made more popular (social norms), easier (self-efficacy), and more fun (better perceived consequences) than a competing behavior. The new media clearly have terrific potential to accomplish that. But if the new media are to fulfill their promise, health professionals will have to be proactive. For example, one widespread hope is that interactivity will lead to better decisionmaking based on easier access to experts and a wider range of information. But some studies show that when users are offered multiple interactive services, peer support is the most heavily used.

Four things must be kept in mind. First, people differ. The Internet will not homogenize them. Differences must be understood, respected, and addressed through targeted programs. Good epidemiology, lifestyle research, and behavioral observation will still be needed. Second, people will use the Internet the same way they used its predecessors: to solve problems and to entertain themselves. Health information services offered through the new media should be entertaining as well as didactic. Third, the new media will probably be used in ways that will surprise health professionals. People do not always use technology for the purposes it was originally intended. Fourth, the new media do offer many opportunities. Their interactivity and storage capacity can help improve decision-making, particularly for complex treatment issues. It will be exciting to explore the potential to shape social norms over the

Internet. The new media also offer potential for developing confidential skill training for people engaged in high-risk behaviors. And they are entertaining, so learning, deciding, and doing may be more fun than ever before.

Panels

The Informed Consumer: Self-Care, Self-Help, and Selecting Health Care, *Ed Madera, American and New Jersey Self-help Clearinghouses, Northwest Covenant Medical Center, moderator.*

The growth of both the self-care and self-help group movement reflects the increasing determination of Americans to be active participants in improving and managing their own health and in choosing the most appropriate health care services. Member-run self-help groups and consumer-operated services offer a significant option for reaching and partnering with specific populations that have practical experiential knowledge to share and joint advocacy interests to promote, such as those with severe physical disabilities or rare disorders or those caring for loved ones with chronic illnesses, who are now increasingly able to meet on the Internet. However, the health care system of resources, power, social, and organizational structures has traditionally served to limit consumer and patient access to information and to restrict the individual's ability to make informed choices. It will be necessary to identify and highlight partnerships that significantly involve consumers in active roles in networked health information initiatives. Increased professional training and continuing educational efforts for providers can convey the positive aspects and efficiencies of consumer involvement, empowerment, evaluation, and partnerships in the new managed care information age.

Health Information for Everyone, *Linda Neuhauser, Ph.D., University of California, Berkeley, moderator.*

Many underserved populations in the United States do not have access to or skills for computers or live in rural areas away from key online services. "Front end" services will need to organize the information in a way that is user-friendly, culturally and linguistically relevant, and accessible. The users should be involved in an ongoing process of design, testing, continuous enhancement, and effective promotion of the system. One model from the California Alliance of Information and Referral Services builds a statewide database of health and human services that will be available through libraries, social service organizations, HMOs, and corporations. Another, LatinoNet, builds a grass roots online system for Hispanic users. A third model builds a statewide—

and ultimately nationwide—standardized directory of health and human services providers, linking consumers to information through print and online phone directories.

Health Information for Managing Demand, *James F. Fries, M.D., Stanford University Medical School, moderator.*

The management of need and demand is a central requirement for organized systems of care, both to improve members' health and to moderate costs. Interactive systems can successfully impact health service use, drug compliance, and adherence to rehabilitation programs. Some of these systems include computer-individualized, mail-delivered programs, applications offering multiple functions related to specific health problems, the time-oriented computer data bank, and the electronic medical record. Quality standards must be developed for such programs and impartial economic analyses must be obtained to document their effectiveness. Programs for indigent/Medicaid settings should be developed.

Put Prevention into Practice, *Hurdis Griffith, Ph.D., U.S. Department of Health and Human Services, moderator.*

Clinical preventive services, such as counseling, screening, and immunizations are not being provided at the level recommended by major authorities. *Put Prevention into Practice* is a set of materials to assist patients and providers in knowing what is needed and when. The key publications are available in print and online, including the *Clinician's Handbook of Preventive Services* and the *Personal Health Guide.* The development of a fully automated system, including links to the patient in the home, would promote appropriate demand and delivery of preventive services and make it easier for patients and providers to manage individual health care.

Technology for Health Decisionmaking, *Al Lazar, Agency for Health Care Policy and Research, DHHS, moderator.*

The pursuit of improved health care has broadened to focus on the provider-patient relationship as an active partnership. In this partnership, the patient's involvement in the decisionmaking process is vital to satisfactory outcomes. Patients and caregivers need tools to help them sort out a complex body of health information, assess the patient's individual situation, and weigh care alternatives against the values and priorities of the patient and family. The new media offer promising opportunities, but research is needed on the effectiveness of such tools for patient satisfaction and on health outcomes. Quality assurance

standards are also needed to ensure the integrity of the content and the decisionmaking structure of the technologies involved.

The Economics of Networked Health Information, *Bruce Kingma, Ph.D., State University of New York at Albany, moderator.*

While technology has provided methods for lower cost delivery of higher quality information to the consumer, the roles of private, public, and nonprofit organizations in financing the creation, delivery, and access to information must be determined. The economic issues are shaped by costs and benefits, copyright and ownership, accuracy, privacy, pricing, storage, access by information "haves" and "have-nots," creation, distribution efficiencies, and the social value of improved health status and reduced demand for medical care. Distributed architectures, integration and aggregation of information for managed care, physician group practices and hospitals, and inclusion of consumers in the health care information value chain will dramatically alter the economics of health care. More research is needed to determine where cost savings occur from health information networks.

Empowering Community Intermediaries, *Nancy Milio Ph.D., University of North Carolina at Chapel Hill, moderator.*

Small community-based organizations (CBOs) are important intermediaries between local individuals and groups and larger institutions beyond the community. They inform and support the individuals they serve, deliver services, and advocate for community resources. Community information technology (IT) can become not only a way to deliver health, social, education, and business information and services, but also a vehicle for organizational development and advocacy. Health professions should expand the focus of their IT to include CBOs. Increasingly burdened public health organizations should examine the public health interest in closing the gap between IT-poor and IT-rich organizations and develop a strategy for building inclusive electronic webs with CBOs.

Intellectual Property and Networked Consumer Health Information, *Fred Cate, J.D., Indiana University School of Law—Bloomington, moderator.*

While the intellectual property issues associated with networked consumer health information are not unique, their resolution may be affected by special features of that information. For example, the government is a significant funder and originator of health-related information. Much of consumer health information is of great importance to the

population and benefits not only individuals, but also employers, insurance companies, the government, and society as a whole. Because of these and other considerations, the government must continue to provide particularly important health information to the public and facilitate that information's accessibility and reliability, while avoiding unnecessary competition with private information providers. Congress and the courts must modify or interpret current copyright law as necessary to guarantee that it does not interfere with innovation in tailored information services and products or exceed its constitutional boundaries and restrict access to information, as opposed to expression.

Conclusions

Networked health information is clearly of great potential value to individuals and families, health care providers and insurers, companies and communities, and public and private agencies. The private sector may become increasingly involved out of its own self-interest, or with the encouragement of public laws and incentives. The government may have to become more active in addressing issues of quality and access. At a minimum, the Federal government may have an obligation to ensure that standards are developed and applied to the information it produces and to improve access to its own networked information for people in their homes and their community-based intermediaries such as public libraries, schools, government agencies, and community service centers. These standards and access priorities may be applicable to the broader body of networked consumer health information. Yet another key issue, not fully addressed by this conference, is privacy. The user must be assured that technical and other systems ensure the confidentiality of all searches for health information.