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Report to the Chairman,
Subcommittee on Human Resources
and Intergovernmental Relations,
House Committee on
Government Reform and Oversight

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CONSUMER HEALTH INFORMATICS

Emerging Issues



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The Honorable Christopher Shays
Chairman, Subcommittee on Human Resources
and Intergovernmental Relations
Committee on Government Reform and Oversight
House of Representatives

Dear Mr. Chairman:

Technology today increases the availability of health information to the individual, allowing the consumer to become better educated and more involved in his or her own health care. Government and private health care organizations rely on a wide array of technologies to disseminate health information on various topics, including preventive care, illness and injury management, treatment options, and post-treatment care.

In response to your request, this report presents the results of our review of consumer health informatics—the use of modern computers and telecommunications to support consumers in obtaining information, analyzing their unique health care needs, and helping them make decisions about their own health. We defined what is meant by consumer health informatics; we then obtained data on (1) the demand for health information and the expanding capabilities of technology, (2) users' and developers' views on potential systems advantages and issues surrounding systems development and use, (3) government involvement—federal, state, and local—in developing these technologies, and (4) the status of related efforts by the Department of Health and Human Services (HHS). As part of this review, we surveyed consumer health informatics experts, and present their views on the issues that need to be addressed when developing consumer health information systems. Experts' views were also collected at a GAO-sponsored conference in November 1995.

Results in Brief

While administrative and diagnostic hospital-based information systems have used computer technology for over 30 years, public- and private-sector organizations have only in the past 10 years or so developed the capability to disseminate health information to millions of people nationwide. Over the past decade, in fact, several hundred new consumer health information systems—called informatics—have been developed. Today's consumers are demanding more—and more detailed—health

information, and are taking a more active role in making medical and lifestyle decisions.

Studies on the value of consumer health informatics have highlighted the systems' ability to respond to consumers' information needs quickly and efficiently, and reduce the need for some unnecessary medical services, thereby lowering health care costs. The systems are capable of providing many different types of information—often customized—with which consumers can, for instance, review the pros and cons of elective surgery or provide physicians with preoperative health information, potentially avoiding unnecessary preoperative tests.

Those involved in developing such systems point to additional benefits: One informatics developer stated that an informatics system helped doctors detect signs of alcoholism more frequently when patients completed a computerized interview before an office visit. (The finding was that alcoholics tended to be more honest when they responded to a “nonjudgmental” computer than they would have been if interviewed in person.) These tools of technology are not intended to replace human contact with medical providers but, rather, to enhance the usefulness of those encounters.

While recognizing that technology appears to offer a number of promising opportunities, experts in consumer health informatics also identified several issues—including access, cost, and information quality—that they believe will need to be addressed to effectively and efficiently develop, maintain, and use such systems. They also identified options for addressing these issues, including encouraging public- and private-sector partnerships, using the skills of an interdisciplinary team of professionals for development, and following sound systems development practices.

The federal government is a major disseminator of health care data, providing information and funding to millions of Medicare and Medicaid recipients, federal employees, and veterans. Federal agencies also provide health information to the general public through print, electronic, and telephone services. State and local governments also are involved in supporting informatics projects and providing health information on-line to citizens. While HHS and other government agencies have developed and tested several informatics projects, no single, comprehensive inventory of such projects exists; the total cost of all government activities is also unknown. HHS has, however, recently completed a report that, according to agency officials, outlines possible future steps to enhance health

information for consumers and promote collaboration across federal agencies.

Background

Hundreds of consumer health informatics systems have been developed over the past decade and have grown in technical sophistication, from simple programs designed in a few days to advanced clinical tools built by teams of experts over several years. Topic content also varies widely, including general information and advice from physicians and nurses in areas such as nutrition, smoking cessation, and disease management, and more individualized information tailored to consumers' responses on health inventory questionnaires. Individuals suffering from specific diseases or conditions get the chance through technology to share their experiences on electronic "bulletin boards" or "chat lines," making these experiences available to others who may not know anyone in the same situation.

The federal government provides consumers with publications both in writing and via computer, through such agencies as HHS' Office of Public Health and Science, National Institutes of Health, and the Department of Agriculture's Food and Nutrition Service. The government also provides health and medical information through the Internet¹ and various commercial on-line services, as well as through clearinghouses that maintain computer databases. States and local governments also have supported consumer health informatics and have provided medical information and health articles via the Internet. The private sector, too, has played a role in disseminating health information; many health organizations, universities, insurers, and nonprofit organizations are currently involved in informatics projects.

Objectives, Scope, and Methodology

For this review, we were asked to contact consumer health informatics experts in both the public and private sectors to gain an understanding of how computer and telecommunications technologies are being used to provide health information to consumers.² This inquiry included questions on the costs, potential benefits, and other issues associated with the development and use of such systems; we also examined federal, state,

¹The Internet connects thousands of networks to produce the world's largest group of connected computers. These networks belong to a variety of groups, including government bodies, universities, businesses, local library systems, and schools. Once connected to the Internet, a user can access databases and bulletin boards, perform research, obtain information, print material, and participate in on-line discussion groups.

²We did not independently verify the information provided by these experts.

and local government and private-sector activities that develop and/or sponsor these projects.

To address these objectives, we searched the literature to obtain and review information on the status, development, and use of informatics. We also contacted 80 consumer health informatics experts representing federal and state agencies, private health organizations, and universities. We developed a structured questionnaire and interviewed these officials at length to learn more about the development of consumer health informatics projects, obtain information on the different types of technologies used, and identify other emerging issues related to informatics. (Appendix I lists the experts interviewed.) In addition, we gathered evaluations of consumer health informatics projects from these experts and other published sources, and identified reported costs and benefits of using such technologies. Using this information and interview results, experts identified issues related to consumer health informatics and options that could help address them. We did not independently evaluate these projects; rather, we are reporting the views of the experts we interviewed. Then, in November 1995, we convened a panel—12 of the 80 consumer health informatics experts—to further discuss these topics. (Appendix II lists the panelists.)

Also, we interviewed officials within HHS at the Agency for Health Care Policy and Research, Centers for Disease Control and Prevention, Food and Drug Administration, Health Care Financing Administration, National Cancer Institute, National Library of Medicine, Office of the Assistant Secretary for Planning and Evaluation, and Office of Disease Prevention and Health Promotion. In addition, we interviewed officials of the Departments of Agriculture, Commerce, and Defense; the Office of Management and Budget; and the Social Security Administration, to obtain information on the status of the Vice President's request that HHS develop recommendations for federal activities to provide health information to consumers.

Finally, we queried Internet users to obtain information on the different types of health information sources available to consumers, and the various ways that consumer health information is disseminated through the Internet. A total of 103 Internet responses were received and reviewed as part of our evaluation. Also, we observed the operation of six consumer health informatics projects, and witnessed computers and communications technologies in use providing health information to consumers. We conducted our review from September 1995 through

April 1996, in accordance with generally accepted government auditing standards.

Demand for More Information Helps Drive Expanding Capabilities of Technology

Many Americans are now requesting more health care information to help manage, in concert with their health care providers, their own health. The growth in the need for health information has placed significant demand on traditional information sources. Informatics offers a new avenue through which consumer needs for information may be met. Consumers also have easier access to various technologies, including personal computers, CD-ROMs,³ and on-line services, allowing them to obtain health information on nearly any subject within minutes.

Consumers' high and increasing demand for health information has been demonstrated in a number of studies. One report indicates that telephone inquiries to Public Health Service's health information clearinghouses more than doubled in the early 1990s, while mail inquiries grew by 43 percent.⁴ Another recent survey indicated that more than two-thirds of consumers have questions about their personal health, such as questions on illness prevention or disease management.⁵ Public libraries reported in 1994 that 10 percent of all reference questions are health-related, accounting for 52 million inquiries annually. Similarly, voluntary health agencies, such as the American Cancer Society, the American Heart Association, and the American Lung Association, have reported reaching 82 million potential consumers with health information, and answering over 4 million direct inquiries each year.⁶ Despite this interest, however, in a 1994 survey published by the Medical Library Association, almost 70 percent of the respondents reported problems in gaining access to appropriate health information. When queried, 60 percent said that they would be willing to pay for an easy way to access an integrated resource to provide such health and wellness information.⁷ In fact, several

³An acronym for *compact disc read-only memory*. The compact disc is a nonmagnetic, polished metal disc with a protective plastic coating, used to store information in digitized form. The disc is read by an optical scanning mechanism that uses a high-intensity light source, such as a laser. Use of CD-ROMs provides rapid and flexible searching of large volumes of data.

⁴J. Michael McGinnis, Mary Jo Deering, and Kevin Patrick, "Public Health Information and the New Media: A View from the Public Health Service," *Health and the New Media: Technologies Transforming Personal and Public Health*, ed. L. Harris (Lawrence Erlbaum Associates, 1995), p. 132.

⁵Mary Jo Deering and John Harris, "Consumer Health Information Demand and Delivery: Implications for Libraries," *Bulletin of the Medical Library Association*, vol. 84, no. 2 (April 1996), pp. 209-216.

⁶McGinnis, Deering, Patrick, *Health and the New Media*, p. 133.

⁷Council on Competitiveness, *Highway to Health: Transforming U.S. Health Care in the Information Age*, March 1996, p. 29.

informatics projects have been developed by consumers frustrated by their inability to find needed information for their own health conditions or those of friends or family.

The need for information is particularly apparent in self-care situations, for example when dealing with one's own minor injury or illness. According to the president of Healthwise, Inc. (a nonprofit center for health care promotion and self-care research and development), approximately 80 percent of all health care involves problems treated at home.⁸ Effective management of these problems can prevent the illness or injury from progressing to the point of needing professional intervention. The vice president for product management at the Center for Corporate Health, Inc., estimated that as many as 67 million clinical visits are unnecessary or highly discretionary, and that many of these could be avoided if the proper health education materials and decision support tools were provided earlier.⁹ For this to happen, however, consumers' self-treatment must follow the correct self-diagnosis. If a consumer misdiagnoses his or her health problem and then goes on to "treat" it, benefits from automated dissemination of information could be negated and may even result in higher medical costs.

Advances in technology make access to consumer health information easier, responding to this increasing consumer demand. As reported in 1995 by the Council on Competitiveness, 37 percent of U.S. households had computers, and that number was expected to reach 40 percent by the beginning of 1996.¹⁰ The use of technology in schools is also on the rise. Quality Data, Inc. annually publishes "Technology in Public Schools," and reported that the number of computers in the nation's classrooms reached 2.3 million in the 1991-92 school year. This figure has grown steadily, reaching about 4.1 million for the 1994-95 school year. Just within the last few years, according to the March 1996 Council on Competitiveness report, the consumer market for CD-ROMs has flourished. In 1993, 5 million were sold, for an estimated \$202 million; in 1994 sales had more than quadrupled, to 22.8 million, for an estimated \$648 million.

In addition, the use of the Internet and commercial on-line services (such as America Online, CompuServe, and Prodigy) has grown. The

⁸Donald W. Kemper, seminar on the Healthwise Communities Project, Healthwise, Inc., Dec. 12, 1995.

⁹Allen Douma, "The Art and Science of Demand Management," Association for Worksite Health Promotion, vol. 2, no. 3 (summer 1995), p. 10.

¹⁰Council on Competitiveness, Highway to Health, p. 34.

Congressional Research Service reported that the Internet is the fastest growing communications medium in history. Between 1993 and 1994, the Internet network doubled in size, as it has done yearly since 1988. The Internet is estimated to reach between 15 million and 30 million people, with 1 million new users each month.¹¹ Many Internet users are retrieving health information, joining discussion groups to share experiences on specific diseases, and accessing bulletin boards that provide information on medical topics.

What Is Consumer Health Informatics?

Consumer health informatics is the union of health care content with the speed and ease of technology. Informatics systems provide health information to consumers in a wide range of settings.¹² For example, while many people access health information through personal computers in their homes, others access these systems in more public locations such as libraries, clinics, hospitals, and physicians' waiting rooms. Informatics systems have also been targeted to specific groups of people, such as those with specific diseases, as well as handicapped, rural, and high-risk populations. Other systems, such as those that provide their information through the Internet, have been designed to reach even wider audiences.

Consumer health informatics can be organized into three general categories: systems that

- *provide* health information to the user (one-way communication),
- *tailor* specific information to the user's unique situation (customized communication), and
- allow the user to *communicate* and *interact* with health care providers or other users (two-way communication).¹³

The kinds of technologies that provide health information to users include CD-ROMs containing health encyclopedias, on-line health articles, bulletin boards, and telephone systems automatically connected to databases that provide consumers with appointment reminders. Software packages complement the computer hardware, with products designed to help people learn how to perform specific simple medical functions, such as using a thermometer or injecting insulin. Systems that tailor information to

¹¹Congressional Research Service, 1994a, Welcome to Cyberia: An Internet Guide, CRS Issue Brief, Washington, D.C.

¹²Tim Kieschnick, Linda J. Adler, Holly B. Jimison, 1996 Health Informatics Directory (Williams & Wilkins, 1996), p. 1.

¹³Kieschnick, Adler, Jimison, 1996 Health Informatics Directory, p. 2.

the individual include automated systems that obtain information from the consumer about his or her general health or other health-related factors (such as family disease histories and smoking habits) and, on the basis of this information, suggest a need for preventive health procedures (such as mammograms), or identify actions to curb high-risk behaviors.

Finally, some examples of the interactive category include informatics systems that allow users to communicate with other individuals, such as health care professionals or other users, through such means as electronic mail, electronic bulletin boards, and on-line discussion groups. Consumers not only obtain professional advice, but also receive support from others who may be experiencing similar health problems. For example, one individual accessing an on-line group for prostate cancer patients noted, "I gained the immense benefit of hearing the experiences and opinions of several prostate cancer patients and survivors. I believe that accessing this material saved my life."

Types, Sponsors, Costs Vary

We surveyed managers of 65 informatics projects currently in operation and 13 under development, covering a wide range of informatics types and technologies. Table 1 presents a sample of the different types of informatics projects covered in our review, including various target users and technologies employed.

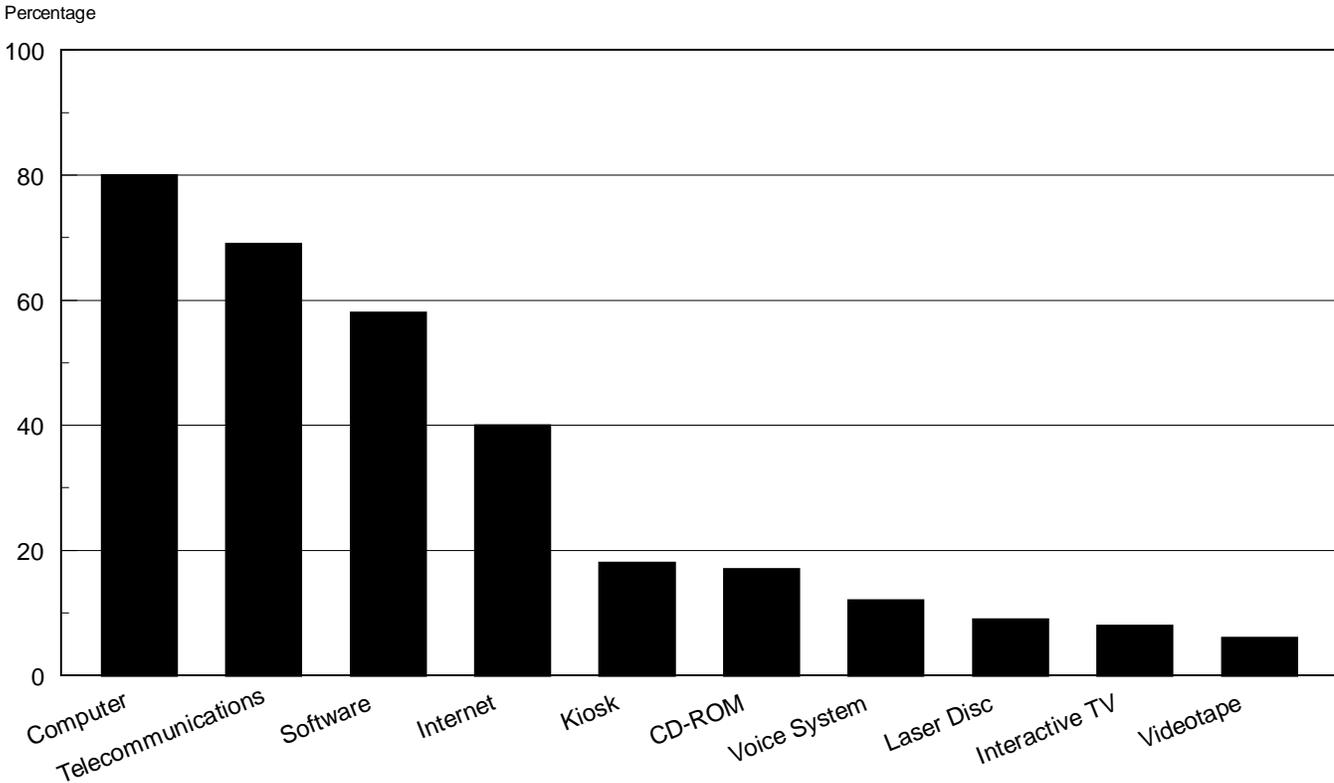
Table 1: Sample of Informatics Projects by Location, Description, Target Users, and Technology Employed

Project/location	Description	Target users	Technology
Shared Decision- making Various nationwide locations	Health information system for disease management and decision support	Patients with illnesses requiring treatment decisions, such as cancer and prostate disease	Personal computers, computer software, laser discs, videotapes, and touch-screen monitors
HealthQuiz PreScreen Various nationwide locations	Hospital/clinic-based system designed to collect medical history information directly from a patient before surgery	Patients scheduled for surgery requiring anesthesia	Computer hardware and software
ComputerLink Cleveland	System linking health counselors and Alzheimer's caregivers to provide professional advice and peer support	Caregivers of Alzheimer's disease patients	Personal computers and telecommunications
Automated screening systems (HIV-related factors and health histories) Boston	Systems designed to collect health history and lifestyle information from consumers on sensitive issues, such as HIV-related factors and alcohol consumption	Blood donor candidates and patients visiting doctors for various reasons	Computer hardware and software
House Calls Cleveland	System providing health information, support groups, message services, and appointment reminders	Poor, undereducated, chronically ill, and/or drug-addicted individuals and patients	Standard touch-tone telephones connected to a central computer system
Internet and commercial on-line services Available worldwide	Systems providing on-line access to medical information, health advice, and disease management support groups	All types of consumers	Personal computers, computer software, and telecommunications

Source: Informatics projects documents and experts interviewed.

The 78 projects used at least 10 different technologies; most projects, however, involved the use of personal computers, computer software, or telecommunications. Many of the projects used these technologies in combination. Figure 1 identifies these various technologies, and the percentages of projects reviewed in which they played a part.

Figure 1: Technologies Used by GAO-reviewed Projects



Source: 1995 GAO survey of informatics projects managers.

The informatics experts identified a wide variety of sponsors of consumer informatics products and the infrastructure required to support them: technology companies; network providers; health maintenance organizations; organizations that fund health-related research; the entertainment industry; federal, state, and local governments; pharmaceutical companies; nonprofit and community groups; insurers; and health care purchasing groups.¹⁴ Other sponsors include employers, entrepreneurs, universities, volunteer health agencies, and venture capitalists.

¹⁴Steven Locke, Tim Kieschnick, and Susan Pinco, draft position paper of the Working Group on Mechanisms of Sponsorship for the Institute of Electrical and Electronics Engineers Medical Technology Policy Committee, Subcommittee on Personal Health Information Systems, October 1995.

Costs to develop and maintain consumer health informatics systems also vary according to complexity and sophistication. Project officials stated that systems-development costs ranged from very little to \$20 million.¹⁵ These officials added that maintenance costs also ranged from very little to \$1.5 million annually. However, because over half of the 78 projects we surveyed were either in operation for 2 years or less or were under development, many project officials did not have maintenance cost data available. One low-cost system at the National Institute of Diabetes and Digestive and Kidney Diseases was designed to provide health information over the Internet. The system was developed using one of the Institute's surplus personal computers for the project. Another expert from the University of Montana reported that a low-cost Internet system called Healthline was developed by university students as a class project, with the university providing the equipment.

More expensive systems generally are more complex and permit interaction with the user. For example, Access Health, Inc., contracts with insurers, managed care organizations, and employers to provide advice on illness prevention, disease management, and general health information to their enrollees and employees. The company employs 470 people, including 265 nurses and 85 technical support personnel, to conduct research and answer enrollees' and employees' questions, and has spent \$20 million on systems development over the last 7 years.

Users and Developers Cite Potential for Reduced Costs and Other Advantages

Since informatics is a new field, only limited research has been performed to confirm its full monetary value. Some studies have shown, however, that informatics offers the potential to reduce some unnecessary medical services, thereby lowering health care costs. Information technologies can also offer other advantages over hard-copy text material. For example, the consumer can more readily review material at his or her own pace and at the needed level of detail.

Potential Cost Savings

The Shared Decision-making system, an interactive video program, has been developed to help facilitate patient participation in treatment decisions. Health providers ask for personal data about the patient's condition and enter the data into the computer system. The system then analyzes these data and provides tailored information about treatment

¹⁵Project officials did not always quantify all costs. For example, one project official excluded labor costs because existing staff were used. Similarly, other project officials did not quantify equipment costs because they used existing resources or received the equipment from another department within their organization, at no cost.

options, including the potential benefits and risks associated with each option, and the statistical probability of treatment success. According to its developer, this system helps educate the consumer, allowing patients and doctors to function together as a team, creating an environment conducive to informed, shared decision-making.

HHS' Agency for Health Care Policy and Research (AHCPR) and two health maintenance organizations—the Center for Group Health Studies, Group Health Cooperative of Puget Sound (Washington) and Kaiser Permanente (Colorado)—jointly evaluated one program in this system dealing with benign prostate hyperplasia—a noncancerous enlargement of the prostate gland, usually affecting men over 50—and found a 40-percent drop in surgery rates because fewer patients chose the elective surgery. According to AHCPR officials, potential cost savings could be substantial, as this is the second most common surgical procedure performed in the Medicare population; it results in an estimated annual cost to the federal government, according to AHCPR, in excess of \$2 billion.

The American Society of Anesthesiologists, Inc., evaluated a system known as HealthQuiz, and found that Medicare billings were reduced when clinics were required to use a computerized system that collected and analyzed preoperative health-risk test and evaluation information about patients. Centers using HealthQuiz ordered fewer tests, and physicians relied more on the computerized information before recommending additional tests. For example, before implementing the system, standard diabetes tests were given prior to each operation but, according to the anesthesiologists, were only really needed for patients with diabetic symptoms or a history of the disease. Anesthesiologists researched the benefits and said that Medicare realized savings of \$800,000 annually at one preoperative clinic alone, from avoiding or eliminating unnecessary preoperative testing.

At least half of all adults will at some point serve as caretaker to an aging parent, spouse, sibling, or friend. One system—ComputerLink—has been developed and used to help support caretakers of Alzheimer's patients.¹⁶ The Cleveland system provides an electronic encyclopedia that describes over 200 facts about the disease, stories about others' caregiving experiences, and local services that are available. Another feature includes a method by which the caretaker can communicate with other caretakers and with professionals. The system helps the caretaker resolve issues,

¹⁶Patricia Flatley Brennan, Shirley Moore, and Kathleen Smyth, "The Effects of a Special Computer Network on Caregivers of Persons With Alzheimer's Disease," *Nursing Research*, vol. 44, no. 3 (1995), pp. 166-172.

such as choosing living arrangements and adopting safety procedures—for example, taking car keys away from the ill person. This has helped caretakers reduce feelings of isolation; according to one homebound caretaker, it was her “lifeline to sanity.” According to Case Western Reserve University researchers, significant cost savings may occur when caretakers are given access to systems such as ComputerLink and other community-based services because they use fewer traditional health and social services than those without such technical supports—potentially saving taxpayers thousands of dollars.¹⁷ According to these researchers, the cost of implementing ComputerLink—\$84,000¹⁸—was recovered in the first year of implementation.

Other Advantages

Advantages cited by project developers and system users include

- *anonymity*—increased ability to remain unknown while accessing personal or sensitive information, allowing a more accurate representation of health data;
- *outreach*—improved access by individuals in rural and underserved areas;
- *convenience*—the ability to use the system any time, day or night;
- *scope*—increased ability to reach large numbers of people; and
- *support*—ease of establishing on-line relationships with others.

Officials at Harvard Medical School’s Center for Clinical Computing stated, for instance, that patients were more honest with the computer because the system is “faceless and anonymous.” For example, a computer questionnaire identified more potential blood donors who had HIV-related factors in their health histories than did personal interviews by health-care providers. Another automated screening tool for health histories identified a more accurate representation of sensitive health data. Specifically, in the case of one patient, doctors’ notes indicated that “[he] uses alcohol socially”; in contrast, the computer found that the patient had monthly blackouts.

Technological advances have also made it possible to reach out to individuals in rural and underserved areas. One system provides computer services to patients both in and out of the home through a standard touch-tone telephone, without the need for a computer or modem.

¹⁷Fay Cobb Payton, Patricia Flatley Brennan, and J. B. Silvers, Cost Justification of a Community Health Information Network: The ComputerLink for AD [Alzheimer’s Disease] Caregivers, poster, The 19th Annual Symposium on Computer Applications in Medical Care, New Orleans (November 1995).

¹⁸This included a computer terminal and modem being placed in 47 caretakers’ homes, with the necessary power supply, telephone, and communication lines, as well as a nurse to answer caretaker questions and provide health advice.

Dr. Farrokh Alemi, of the Institute for Telecommunications in Public Health, Cleveland State University, has developed several telecommunications systems for integrating patient self-care with clinic care. Patients may leave messages for health professionals via a voice recording; health professionals return voice mail messages 24 hours a day. One entire program supports cocaine-addicted pregnant women. Users who accessed the system at least three times a week, it was found, participated in formal drug treatment groups one and a half times more frequently than did nonsystem users.

Another important advantage of informatics systems is scope; using on-line networks allows information to reach large numbers of consumers. For example, with a computer self-help group, a dozen to 20 people use the computer at the same time and receive instantaneous input from all of the people. In addition, there are currently hundreds of free bulletin board systems in the United States, accessible day and night.¹⁹ A number of bulletin boards focus on addictions, disabilities, diseases, and other health issues. According to one expert, “groups supported by technology help people network, understand their disease, and communicate their needs [to health care providers] more quickly.”

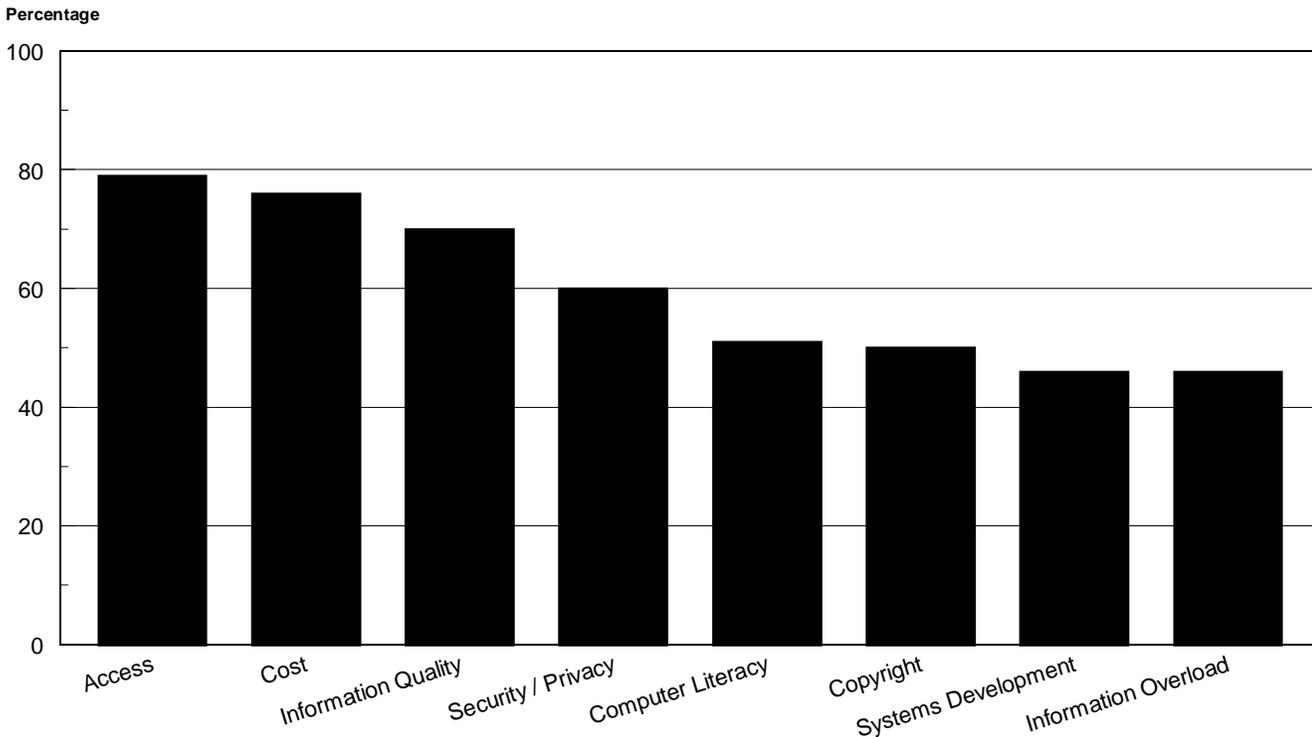
In response to our on-line survey of Internet consumers, we found that consumers value support groups for many different reasons. One consumer said he gains support and understanding from his on-line friends, who know exactly what his disease, chronic fatigue syndrome, is like. A woman said she obtains information from the Internet that she cannot get from her doctors or books about “the true facts from real people living the nightmare of ovarian cancer.” Several consumers said that the Internet provides them with an easy way to get information and that it is often more current and relevant than other resources. In response to our question about the benefits of the Internet, one consumer said that an informed patient can make better decisions; . . . knowing the various options available for patients with prostate cancer can only help the consumer. Finally, a consumer noted that the Internet provides moral support, allowing information and experiences to be shared among many people.

¹⁹Edward J. Madara, “Using High Tech to Find and Form Self-Help Groups for Better Health,” American Self-Help Clearinghouse, prepared for presentation at the Healthy Cities Communication Toolbox Summit Conference, December 1993.

Experts Identify Issues and Options

While technology provides various advantages and may reduce unnecessary medical costs, the health informatics experts in our study acknowledged that computer systems also raise issues that need to be addressed regarding the development and use of consumer informatics. The experts also identified a number of technical and management options to address each of these issues. In response to our questionnaire, the 80 experts identified three issues as most significant: *access*, *cost*, and *information quality*. Other issues identified as important to ensuring effective development and use of consumer informatics included security and privacy, computer literacy, copyright, systems development, and information overload. Figure 2 shows the percentages of experts who judged these issues very significant or significant.

Figure 2: Experts' Views on Relative Significance of Consumer Informatics Issues



Percentage identifying issues significant/very significant.

Source: GAO analysis of 80 experts' views.

Our November 1995 conference panel participants discussed the various options available for addressing these issues, including federal, state, and local government and private-sector involvement in informatics systems development. The pages that follow synthesize the results of that discussion, along with the questionnaire responses.

Access, Cost, Information Quality: Top Issues Related to Consumer Informatics

From 70 to almost 80 percent of the experts rated access, cost, and information quality as significant or very significant issues affecting the future of consumer health informatics. In terms of access, health informatics is largely available only to those with computers, modems, and telephones. At least 6 percent of U.S. households lack telephones,²⁰ and about 60 percent lack computers. Other issues influencing access were physical barriers, such as those affecting residents of remote or rural areas, and physical handicaps, hindering easy access to and use of computers.

Cost issues were also a consideration. The cost of purchasing software, fees for networking and, for some, transportation costs to a library or other public sources of information via computer may also hinder accessibility. Besides the consumer perspective, issues such as how much funding is needed, where funding comes from, and the cost of keeping up-to-date with changes in technology, were important to the experts.

Finally, information quality was raised by the experts as a very significant issue. Ideas expressed dealt with the potential for information to be incomplete, inaccurate, or outdated. One expert told us that CD-ROMS with current dates are in reality based on much earlier, out-of-date research. Experts also said that networks may carry information that has been changed or taken out of context by the on-line service or by consumers themselves. Others identified the potential for biased information that may have been developed by a person or organization with a vested interest. For example, a developer of an informatics system disseminating information on high blood pressure could skew the nature and tone of that information in a way that steers consumers toward a certain kind of therapy, such as a particular type of medication. This could create an artificially high level of demand, which in the long run could cost consumers and society more if patients are taking medications that are harmful or not needed. Our July 1995 report on prescription drugs and the elderly discusses the various factors that contribute to the inappropriate

²⁰Falling Through the Net: A Survey of the "Have Nots" in Rural and Urban America, U.S. Department of Commerce, National Telecommunications and Information Administration, Washington, D.C., July 1995, pages 1, 3, 7, and 11.

use of prescription drugs and possible actions that patients, physicians, and pharmacists may or may not take.²¹

Other Issues Involving Informatics

Other concerns, although seen as less critical, must also be addressed, the experts felt. Security and privacy are essential, particularly on networks, where consumers may want to discuss sensitive health care issues, such as addiction and drug abuse.

Views on copyright and systems development issues were also expressed. Experts noted two distinct sides of the copyright issue. On the one hand, copyright laws protect the copyright holder and the proprietary nature of the computer programs constituting the system so others will not be able to unfairly reap the rewards that rightfully belong to the developers. On the other hand, copyright restrictions can impede the immediate availability of information to the consumer.

Experts noted three issues regarding systems development: (1) compatibility, (2) infrastructure, and (3) standardization. When hardware or software incompatibilities exist, information transfer among systems is hindered because it is difficult for the different media to communicate and exchange information without programming changes and/or additional hardware. Further, no infrastructure exists—computers that link hospitals, clinics, and physicians’ offices—on a completely national and local level. For example, some organizations and doctors have little or no technology in place, and are therefore unable to share critical health-related and patient information with or receive such information from other facilities, public health service organizations, or consumers. Experts further agreed that standards for health care data are lacking and that data-sharing is affected by different data formats. As the Council on Competitiveness reported, a patient’s health history may be organized in an automated format that differs from another format used in electronic medical records maintained by hospitals or other health organizations.²² Experts said, however, that in the future, it is important for consumers to be able to track and record their personal health data across multiple health care providers’ information systems.

²¹Prescription Drugs and the Elderly: Many Still Receive Potentially Harmful Drugs Despite Recent Improvements (GAO/HEHS-95-152, July 24, 1995).

²²Similarly, we testified in 1994 about the lack of standards in automated medical records. See Health Care: Benefits and Barriers to Automated Medical Records (GAO/T-AIMD-94-117, May 6, 1994), p. 4.

Finally, the issues of computer literacy and information overload were mentioned by the experts. Most experts felt that systems are becoming more user friendly, yet cited some people's fear of using computers. The keyboard and mouse are still foreign to some consumers, and may be intimidating. One expert said that many consumers could be afraid to access on-line information services. Further, one expert noted, being on the Internet "is like filling a water glass with a fire hose." Information overload could result if a consumer is overwhelmed with too much technical health information to handle comfortably.

Experts and Users Suggest Options to Address Informatics Issues

Experts discussed several options for addressing each informatics issue, recognizing that the field is young and still evolving. Options ranged from broad practices (such as establishing public- and private-sector partnerships and using diverse and complementary teams of experts to develop informatics systems) to very specific suggestions (such as notifying consumers if the information is from an unknown source) to help address the quality issue. The importance of following sound systems-development guidelines in developing a consumer health information system—such as developing a systems plan, identifying user information needs, and developing technical specifications—was underscored by most of the experts.

Experts noted that establishing public- and private-sector partnerships could address many of the significant issues, especially access. To illustrate, the New Community Corporation (a private, nonprofit organization), the Newark Public Schools, and the University of Medicine and Dentistry of New Jersey, formed a partnership to provide technology to people who lack access to computers. In 1994 and 1995, the partnership was awarded grants of \$107,000 and \$99,800, respectively, from the Department of Commerce's National Telecommunications and Information Administration (NTIA), and began working with the schools and the university to provide students and parents with access to personal computers and various on-line health care services. Public- and private-sector leaders noted that the project was an effective approach to ensuring access and one that could be replicated in other communities. Other options noted by the experts to address access included encouraging the development of consumer informatics for underserved populations and creating innovative ways to provide access. Ideas included partnerships for creating incentives for private industry and government to provide access to systems they develop for the United States and other countries.

In addressing the cost issue, experts indicated that federal, state, and local governments, as well as universities and venture capitalists, could support research to further demonstrate the costs and benefits of consumer informatics. As more research is performed that demonstrates the effectiveness of such systems, interest in developing and using them by many segments of society could increase. One expert said, “the more that individuals are empowered directly in wellness and preventive care issues, the less it will cost the government to pay the health bills; it will be an investment for the future.”

The importance of having a diverse and complementary systems development team of project experts from a variety of fields was also stressed by the experts. For example, experts noted that to help ensure information quality, it is important to include scientists, technologists, community health professionals, and users. Peer reviews of informatics systems developed could also help ensure information quality. One expert noted that projects could be evaluated and rated by various entities, including the American Medical Association and the National Committee for Quality Assurance. Several experts said that the government could monitor information specific to its own area of expertise to help ensure that inaccurate information was not disseminated. For example, the National Cancer Institute could monitor informatics on cancer prevention and treatment. Internet users also suggested that the government could monitor and better organize federal health-related information services, and coordinate and cross-link Internet web sites.²³ Other experts suggested that a consortium of experts in a field could be used, one involving government and private-sector representation, to establish criteria for determining information quality. This group could define guidelines for quality, including issues related to timeliness of data and whether conflicting data exist.

Experts also noted specific options for addressing security/privacy and systems development issues. Regarding security and privacy, systems developers could provide information and education to the consumer and the health provider on how the data would be stored and used. The experts mentioned that sound systems development practices, along with helping ensure that a project is well-designed, can significantly help safeguard the data even if multiple users are involved. Carefully assessing and identifying user needs will also help develop a system that is user friendly and accommodates the target users' needs. For example, when

²³A web site is a discrete location on the World Wide Web (a loosely defined network of information sites that are linked to different Internet storage devices all over the world) that contains information on a specific topic.

designing a system for senior citizens, several developers increased the print size for better visibility. Another developer made special hardware modifications to respond to special needs of handicapped consumers.

**Government
Involvement:
Present Activities,
Future Plans**

The federal government is performing activities to support and review informatics. It develops and tests several projects, provides sources of consumer health information (such as on-line services via the Internet), funds various clearinghouses and information centers, and provides grants to organizations that produce informatics systems. Although some coordination among these activities exists, HHS officials said improvements are needed, and HHS has taken some action. According to HHS officials, the agency has completed a report that describes key ongoing consumer health informatics activities and identifies future steps needed to improve the government's coordination of such activities. Further, a state government expert we interviewed indicated that the state also plans to provide its citizens with health information.

Present Federal Activities

HHS includes consumer information and education among its activities to control disease and improve the health of Americans. Many of its agencies have leadership responsibilities for consumer health services and resource issues relating to access, quality, and cost of care. For example, the Health Care Financing Administration (HCFA) promotes timely delivery of health care information to its beneficiaries. Other major HHS agencies also strive to prevent and control disease by disseminating consumer health information; these include the Centers for Disease Control and Prevention (CDC), the Agency for Health Care Policy and Research, the National Institutes of Health (NIH), and the Food and Drug Administration. Table 2 lists a sample of federal agencies involved in consumer health informatics; their activities are discussed on the following pages.

Table 2: Sample of Federal Government Agencies Involved in Consumer Health Informatics

Department of Agriculture

Food and Nutrition Service

Department of Commerce

National Telecommunications and Information Administration

Department of Defense

Department of Energy

Office of Environment, Safety and Health

Department of Health and Human Services

Agency for Health Care Policy and Research

Centers for Disease Control and Prevention

Food and Drug Administration

Health Care Financing Administration

National Institutes of Health

Office of Disease Prevention and Health Promotion

Department of Labor

Occupational Safety and Health Administration

In recognizing the importance of providing health information to the public, the Congress in 1976 established the Office of Disease Prevention and Health Promotion (ODPHP) within HHS. The office is responsible for coordinating activities related to disease prevention, health information, promotion, and education, and preventive health services within the Department. ODPHP established the National Health Information Center, whose objectives are to identify health information resources, channel requests for information to these resources, and develop publications (both in print and electronic form) on health-related topics of interest to health professionals, health media (magazines, television, and radio broadcasts), and the public. Other federal agencies also share responsibility for providing health information to consumers; these include the Departments of Defense, Energy, and Labor. In addition, the Department of Agriculture administers a variety of programs; its Dietary Guidelines for Americans²⁴ serves as the basis for nutrition guidance to consumers.

Consumers can access federal health information through numerous on-line sources. HHS provides such access to a number of its agencies'

²⁴Developed in coordination with HHS.

consumer health information materials through HHS' Internet home page.²⁵ Other agencies providing on-line consumer health information include the Department of Energy's Office of Environment, Safety and Health; and the Department of Labor's Occupational Safety and Health Administration.

The federal government also operates many clearinghouses and information centers with information on specific health topics. These sources distribute health publications, provide referrals, and answer inquiries; many can be accessed through toll-free telephone numbers. Examples include the Centers for Disease Control and Prevention's National AIDS Information Clearinghouse, the National Health Information Center,²⁶ and the Department of Agriculture Food and Nutrition Service's Food and Nutrition Information Center.

The government has also provided grants for selected projects. For example, the New Jersey informatics project that provides health information via an interactive computer system was funded by the Department of Commerce's NTIA. HCFA, on December 1, 1995, provided a 1-year grant to the University of Wisconsin to use its Comprehensive Health Enhancement Support System (CHESS)²⁷ program in support of Medicare patients. All patients diagnosed with early-stage breast cancer in the geographic area around Madison, Wisconsin, were invited to participate. Physicians in the area are asked to recommend CHESS to their patients. Computers with the CHESS software are placed in the residences of the participants, and a feasibility study of CHESS' effectiveness with the Medicare population will be performed to assess the impact on the participants' health status and treatment decisions, and on the basis of this, determine if the project should be continued and/or expanded to reach more consumers.

²⁵A home page is a discrete location or address on the World Wide Web (a network of information sites that are linked to different Internet storage devices all over the world) that contains top-level information and pointers to more detailed information about an entity or organization.

²⁶The National Health Information Center is a referral service. When health professionals and consumers call in or write, referral specialists search resource files and the Center's database to find organizations that can best respond to their questions. The Center's on-line database directory contains more than 1,100 health-related organizations that provide health information.

²⁷CHESS is an interactive computer-based system to support people facing AIDS/HIV infection, breast cancer, and other health-related crises. The program provides detailed health-related articles, communication with medical experts, support groups, and personal stories, which include individual accounts of people who have coped with the same illness. The system also has programs to help consumers make and implement medical treatment decisions—such as whether surgery or radiation could be used to treat a specific form of cancer.

Further, the administration has emphasized technology issues related to the National Health Information Infrastructure (NHII).²⁸ The National Institute of Standards and Technology awarded to the C. Everett Koop Institute, in 1994, a grant totaling \$30 million—\$15 million in government funds and \$15 million in matching private funds—to develop NHII and to develop the information models and tools required to use the information infrastructure. A public- and private-sector information infrastructure task force was also formed, to research and report on selected technology issues, one being consumer health informatics. One of the task force's working groups, along with HHS, has issued a draft paper on managed care and the national information infrastructure, identifying consumer health education and information systems as a critical component of the health care system.²⁹ Another one of the task force's working groups, with support from HHS and the Office of Management and Budget, has drafted the Consumer Health Information White Paper, which discusses how the federal government can undertake the transition from a predominantly paper-based information service to one using emerging technologies. HHS officials said to further promote public- and private-sector partnerships and advance consumer health information, the agency has begun to hold annual conferences; the first was held in 1995. HHS officials also said the agency has convened its Science Panel on Interactive Communication Technology and Health to help develop a framework for evaluating consumer health information that could be adopted by researchers and commercial developers seeking to improve the effectiveness of their informatics systems. An HHS official said that the panel plans to issue a preliminary report in April 1997.

Current State and Local Involvement

States and local communities are also supporting projects that use technology to disseminate health information to their residents. One large-scale undertaking is the John A. Hartford Foundation-sponsored Community Health Management Information System (CHMIS). Collaborating with several states and local health care organizations, CHMIS provides a community network of health care information, including information on health research and physician data on medical-effectiveness studies. Through December 1995, a total of

²⁸The National Health Information Infrastructure project is a consortium of 14 companies and nonprofit institutions working to create a foundation for developing information management tools that will help remove geographic and economic barriers to health care access.

²⁹Catherine M. Crawford, U.S. Department of Health and Human Services and Health Information and Applications Working Group, Committee on Applications and Technology Information Infrastructure Task Force, "Managed Care and the NHII: A Public/Private Perspective," Health Care White Paper (Final Draft, May 1996).

\$16.7 million has been awarded to Iowa, Minnesota, New York, Ohio, Vermont, Washington, and a Memphis, Tennessee-based group for CHMIS project planning. A possible added benefit of such projects is that they provide an initial framework for the infrastructure that could be used to disseminate consumer information.

On a more local level, in Colorado, Fort Collins' *FortNet* is a network providing health and other types of information. According to the project director, Fort Collins has contributed upwards of \$60,000 over the past 2 years; private and federal contributions are also part of the overall funding mix. A similar project exists in Taos, New Mexico, where the local community enjoys free access to various on-line resources, including directories of local health providers. Financial support comes from the town of Taos, the state of New Mexico, the University of New Mexico, and several private corporations, along with NTIA funding.

Future Federal, State, and Local Plans

To accelerate progress toward an efficient, useful, accessible health information infrastructure, the Vice President in March 1995 requested that HHS lead an interagency group charged with addressing and developing recommendations for federal activities that will enhance the availability of health information to consumers. HHS has recently developed a report that contains information on customer access, the creation of more public- and private-sector partnerships, and efforts to ensure access for various disadvantaged groups. HHS' report also contains information on informatics issues related to federal coordination and research and development. The report was sent to the Vice President on July 18, 1996.

HHS and consumer health experts have recognized that federal coordination of the government's activities in consumer health informatics could be better; other federal activities to improve consumer health informatics coordination are planned. While many federal agencies are involved in providing health information to the public, and many agencies provide health care funding through grants for research, clinical studies, new technology demonstrations, and disease prevention, no single, comprehensive inventory of all this federal activity exists. Several federal entities fund similar vehicles for disseminating consumer health information, and a number of officials noted that HHS offices could benefit from additional information-sharing about their systems-development work to ensure coordination. For example, while NIH officials were developing health information for the Internet web site, they discovered

inadvertently that another NIH office was also converting similar information from written publication to electronic format for an Internet web site. NIH has established a committee to evaluate information to be placed on the Internet web site, and in April 1996 approved a proposal to consolidate information for its various institutes.

CDC also plans to develop an electronic central repository where all of its consumer information can be collected, viewed, and updated. For example, consumer information—covering immunizations, flu, food poisoning, and other illnesses—currently disseminated through kiosks,³⁰ on-line, CD-ROM, fax, and the Internet, will be centralized and more easily accessible. Further, HHS is developing a project called the World Wide Web Gateway to Federal Consumer Health Information. According to HHS officials, the project will bring together in a single database hundreds of brochures and other publications on many health topics, facilitating consumer access. In addition, HCFA is in the preliminary planning stages of a major project called HCFA On-Line. While specific milestone dates for development have not been set, the initial phase is expected to provide information about Medicare provider status; later phases, however, will provide additional health information useful to the Medicare consumer. As part of its development of the system, HCFA is planning to conduct market research to determine consumer health information needs.

In addition to the survey responses from health industry and federal and state government experts, an official from the state of Washington provided insight on that state's involvement in disseminating consumer health information. According to this official, state governments need to establish a strategy for providing health care services and information to consumers. Washington accomplished this by enacting the Health Services Act of 1993, and formally establishing a goal: developing a health care system that improves the health of all residents at a reasonable cost—including one that encourages healthy behaviors and the prudent use of services by consumers. To achieve this goal, Washington plans to develop an automated system with clinical information, information on health care providers, employer health plan enrollment data, health plan payment information, and medical diagnostic and procedure information for consumers. All residents or consumers will be given access to this automated system, managed by community-based organizations and other on-line health services. Washington also plans to evaluate the quality of its

³⁰A stand-alone unit usually consisting of a computer that can receive and process commands, a television screen monitor utilizing touch-screen technology, and possibly a printer to provide output information to the user. Some units also provide video and audio presentations. Kiosks are usually placed in open settings, allowing public access.

health-related information, identify the costs of information services for funding purposes, and safeguard patient and other health-related information by ensuring that only authorized individuals have access. The state may take several years to fully implement these plans to reach all of its citizens but is committed to that goal.

Local involvement in consumer health informatics is expected to continue as well. For example, the local communities involved in the CHMIS projects plan to provide expanded services over the established networks—additional content areas to serve the health-information needs of their consumers.

Observations

Consumer health informatics is a young and emerging field. Multiple players are involved in a variety of different ways, including: for-profit and nonprofit companies; health maintenance organizations; volunteer health agencies; federal, state, and local governments; and community-based organizations, as well as consumers themselves. Formal evaluations have been limited, yet the potential of this tool for increased information access and consumer involvement in individual health care appears promising. Many such systems are enthusiastically supported by their users, but comprehensive studies assessing the use of health informatics by large numbers of consumers, along with other factors that influence illness prevention, disease management, and their associated costs, have not been completed. As the use of informatics systems increases, the benefits and risks—tangible and intangible—may become more apparent. At that time, whatever trade-offs are involved in the widespread use of consumer health informatics could become easier to measure.

Agency Comments and Our Evaluation

In commenting on a draft of this report, the Department of Health and Human Services generally agreed with its thrust, offering additional information and clarification, as well as editorial suggestions. These comments have been incorporated into the report as appropriate. HHS commented on the three areas discussed below.

HHS officials also said that a counterbalancing issue to informatics quality is the potential for “censorship.” While the experts on our panel and several that we interviewed were concerned that inaccurate information could be disseminated to consumers, a means of avoiding this without possibly creating a “censoring” role at the same time is not, HHS officials believe, a simple matter. HHS added that a small group of experts, meeting

at the 1996 HHS-sponsored Partnerships for Networked Consumer Health Information conference, have begun to frame recommendations in this area.

Finally, HHS officials cautioned that it is misleading to say that no inventory of consumer health informatics activities exists, since the National Health Information Center maintains a comprehensive database of consumer health information activities in the public and private sectors. Our analyses showed that this database does act as a health information referral service and lists organizations and government offices that provide health information upon request; it is not in our view, however, a comprehensive inventory of federal consumer health informatics systems or activities. HHS officials further noted that an effort to develop an inventory may be inappropriate because it would be outdated by the time it was published, given the fast pace of development in this area. While we acknowledge that keeping an inventory completely up to date would be difficult, we continue to believe that maintaining an up-to-date inventory of federally sponsored informatics systems offers great value to consumers and the federal government. Consumers would be provided with one current source for all federal activity in this area and federal decisionmakers could get a better sense of what type of federal investment is being made in consumer health informatics initiatives; this information would likely be helpful in examining options for public- and private-sector partnerships, and in encouraging agency coordination and accountability.

We are sending copies of this report to the Secretary of Health and Human Services, the Director of the Office of Management and Budget, and interested congressional committees. Copies will also be made available to others upon request.

Please call me at (202) 512-5539 if you or your staff have any questions concerning this report. Major contributors are listed in appendix III.

Sincerely yours,

A handwritten signature in black ink, appearing to read "Patricia Taylor". The signature is fluid and cursive, with a large initial "P" and "T".

Patricia T. Taylor
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Abbreviations

AHCPR	Agency for Health Care Policy and Research
AIDS	acquired immunodeficiency syndrome
CDC	Centers for Disease Control and Prevention
CD-ROM	compact disc read-only memory
CHES	Comprehensive Health Enhancement Support System
CHMIS	Community Health Management Information System
CRS	Congressional Research Service
GAO	General Accounting Office
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
NHII	National Health Information Infrastructure
NIH	National Institutes of Health
NTIA	National Telecommunications and Information Administration
ODPHP	Office of Disease Prevention and Health Promotion

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