CONSUMERS AND HEALTH INFORMATICS

HEARING

BEFORE THE

SUBCOMMITTEE ON HUMAN RESOURCES
AND INTERGOVERNMENTAL RELATIONS

OF THE

COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT HOUSE OF REPRESENTATIVES

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SECOND SESSION

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CONSUMERS AND HEALTH INFORMATICS

FRIDAY, JULY 26, 1996

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HUMAN RESOURCES AND
INTERGOVERNMENTAL RELATIONS,
COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT,
Washington, DC.

The subcommittee met, pursuant to notice, at 10:10 a.m., in room 2154, Rayburn Building, Hon. Christopher Shays (chairman of the subcommittee) presiding.

Present: Representatives Shays, Morella, Towns, and Barrett.

Staff present: Lawrence J. Halloran, staff director and counsel; Christopher Allred, Kate Hickey, and Robert Newman, professional staff members; Thomas M. Costa, clerk; and David McMillen, minority professional staff member.

Mr. SHAYS. I would like to call this hearing to order and welcome our witnesses and our guests.

How health information is shared can reflect the values of a society, and can help sustain the identity of a culture.

Medicine men of the Lakota Sioux Tribe preserved the rituals and lore of the past while dispensing the wisdom and advice needed to sustain their future. Peruvian shamans were consulted on ways to avoid disease, concoct herbal cures, or increase crop yields.

Today, we gather round the electronic equivalent of the tribal campfire, the computer terminal, the telephone, the Internet screen, to discuss new ways our culture is beginning to share health information. Just look around you. It's called health informatics: the use of computers and telecommunications technologies to help consumers obtain health information, analyze their unique health care needs, and make decisions about their own health.

It has emerged because consumers are asking for access to more and better information about health issues. And they are taking a more active role in making medical decisions. Because the growth of informatics presents important issues in terms of cost, data quality, accessibility, and privacy, we asked the General Accounting Office [GAO], to review the status and the prospects of current informatics efforts.

Specifically, we asked what potential does informatics have to reduce costs and to improve health care for residents of inner cities, rural areas, the elderly, and persons with disabilities. We also asked what roles the Federal, State, and local governments and the private sector might play in facilitating the development and use of informatics technology.

In theory, these systems should be able to provide consumers with the types of information they need at a level of detail they want and at a time, place, and pace they choose. Informatics systems can answer a patient's questions about a specific disease or surgical procedure. Other systems remind patients of appointments.

Studies also suggest that health informatics has the potential to save health care costs, as better informed consumers use medical services less frequently and more appropriately. In one example we will hear about today, doctors found they obtained more candid information on alcohol use by some patients who completed a previsit questionnaire on an impersonal computer system they considered objective and nonjudgmental.

In another case, an interactive video program informed patients of options in dealing with noncancerous prostate enlargement, resulting in a 40-percent reduction in elective surgeries.

And the GAO found that consumers place greater value on Internet support groups, where patients share their knowledge, their experiences, and often their most personal hopes and fears with the real experts, other people facing the same health problems.

A care giver for an Alzheimer's patient called her Internet link her lifeline to sanity. One man said what he learned from other cancer sufferers on the Internet had saved his life. Ironically, we use impersonal technology in an effort to restore a lost sense of communal healing. We gather around the medicine man's campfire to share the accumulated wisdom of our tribe.

The GAO will describe the results of their study of informatics in testimony today. We will also hear about and see the work of five informatics pioneers whose systems are bringing health information to patients in places and in ways not even contemplated, much less practical or practiced just a few years ago.

We are grateful for all our witnesses and exhibitors for their part in this review of where we are and where we might go in the development of health informatics. And we sincerely look forward to everyone's testimony who's here today.

It's my pleasure to recognize my colleague, Mr. Towns, who has been in the forefront of many of the issues that we have talked about in this committee over the years.

Mr. TOWNS. Thank you, Mr. Chairman. And let me begin by thanking you for holding this hearing. I find this subject most intriguing, and I'm pleased we are asking, what is the appropriate Government role early in the game rather than second-guessing the administration after the fact.

I welcome Mr. Omar Wasow to today's hearing. Mr. Wasow resides in the 10th Congressional District in Brooklyn, which I represent. He is the creator of New York Online. New York Online was described by the New York Times as "the hippest" online service in America. Now, I'm not sure I would look to the New York Times to define "hip," but I do like the way Mr. Wasow and his partner, Mr. Hoyes, describe New York Online: "A jazz joint on the digital frontier."

Today, we are looking at systems that deliver health information using modern technology. There are several different systems out

there. Some use telephones, others computers, some target specific audiences, persons with specific diseases. Others are more general. For yet others like New York Online, health is only one part of a package of information services being provided.

What is important in all of this is that there are creative ways to get more information to people about the health problems and health solutions.

We will also hear from the Department of Health and Human Services. They will describe some of the things the Federal Government is doing to promote improved methods of getting health information to the public.

There are health information projects going on all over the Government. GAO will talk about many of those, including projects funded by the Department of Commerce focused on urban problems and projects funded by the Department of Agriculture focused on rural problems. With this information in hand, we can begin asking questions about the appropriate role of the Federal Government in promoting health informatics.

I look forward to working with you, Mr. Chairman, to develop sound policy in this area and to eliminate as much of the confusion as possible. I'm optimistic. You know, I know this is a very complicated and difficult subject to tackle. But when we have you and, of course, when we have people like Mr. Clinger and people like Ms. Collins and, of course, I'm certain that we have a legislative "dream team" that will bring about some real sound policy here that will make lives for all of us much better.

Thank you, and I yield back.

Mr. SHAYS. We're going through a little bonding. [Laughter.]

Our witnesses today are Ms. Patricia Taylor, Director of Health, Education, and Human Services Information Systems, General Accounting Office; Dr. Mary Jo Deering, Director of Health, Communications and Telehealth, Department of Health and Human Services; and they're accompanied by Leonard Latham and also Christie Motley; is that correct?

Ms. TAYLOR. They're both on my team.

Mr. SHAYS. Pardon me?

Ms. TAYLOR. They're both with the General Accounting Office.

Mr. SHAYS. OK. That's great. But we'll swear in all of you, because we may be hearing from all of you. If you would stand, which is our practice. We swear in everyone, including Members of Congress.

[Witnesses sworn.]

Mr. SHAYS. For the record, our witnesses have responded in the affirmative. Ms. Taylor, we'll start with you. We welcome your testimony. I turn the clock on for 5 minutes, and if you go over, I turn it on again. And if you go over a third time, then we'll talk about it.

STATEMENTS OF PATRICIA TAYLOR, DIRECTOR OF HEALTH, EDUCATION AND HUMAN SERVICE INFORMATION SYSTEMS, GENERAL ACCOUNTING OFFICE, ACCOMPANIED BY CHRISTIE M. MOTLEY AND LEONARD J. LATHAM, GENERAL ACCOUNTING OFFICE; AND MARY JO DEERING, DIRECTOR OF HEALTH COMMUNICATIONS AND TELEHEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Ms. TAYLOR. Good morning, and thank you, Mr. Chairman.

Mr. SHAYS. Good morning.

Ms. TAYLOR. I would like to provide a summary of my written statement that has already been submitted for the record. It's a pleasure to be here to discuss our recent survey of consumer health informatics.

Mr. SHAYS. I'm going to interrupt you, because you just made me realize I didn't do all my job. I'm sorry. I need to ask for some unanimous consents while both the Republicans and Democrats are in the chamber. So I ask unanimous consent that all members of the subcommittee be permitted to place any opening statements in the record and that the record remain open for 3 days for that purpose. Without objection, so ordered.

I ask unanimous consent that our witnesses be permitted to include their written statements in the record. Without objection, so ordered. Thank you. Sorry to interrupt.

Ms. TAYLOR. That's OK. It's a pleasure to be here to discuss our recent survey of consumer health informatics, which can broadly be defined as the use of technology to provide health care information to individuals. Our report on this subject is being released today at this hearing.

We interviewed 80 experts in the field of informatics and conducted a panel with 12 of these experts here in Washington. We reviewed over 100 responses to a survey that we sent out on the Internet and identified about 78 informatics projects. There's an increasing demand for more and more detailed health information, and people are interested in becoming more actively involved in making medical and lifestyle decisions that affect them.

Despite a growing interest in this kind of information, about 70 percent of respondents to a 1994 Medical Library Association survey reported that they had problems getting health information. About 60 percent said they would be willing to pay for easy access to integrated health information.

This increasing demand, then, has driven the development of consumer health informatics systems. In fact, a number of the experts we interviewed had developed systems to address information needs about their own health conditions or conditions with their family members or friends.

Now, there are three general categories of technology that are used in informatics. At the low end, you have your telephones and voice mail systems. Kind of in the middle are your television and video programs. And then, of course, at the high end are the computers.

And there are also three general types of systems, some that provide one-way communication. An example there would be if you went to a library and pulled up an online article and read it there.

Other systems tailor information to meet your specific needs. For example, you could go to your doctor's office, fill out a questionnaire, and then based on your responses, they might come up with an exercise program for you. And then finally, interactive systems, which get a lot of press these days. These could be either voice mail systems or online connections between physicians and users or users and other users.

Now, there have been some reported monetary benefits from informatics that result from consumers being better educated and from consumers being able to avoid in some cases unneeded services. For example—and you mentioned this example—there was a 40 percent reduction in elective surgery for individuals with noncancerous prostate conditions who participated in an interactive video program. This could, of course, have an impact on Medicare outlays, since this is the second most common surgical procedure, and it costs the Government about $2 billion a year. Other reported benefits include anonymity. People tended to feel more comfortable and honest or able to feel more honest when they interacted with the technology. And in this case, you could identify substance abuse a little bit better or HIV.

Also, scope and outreach are other benefits. The technology helps you reach a wider and larger audience. People reported benefits with convenience, in that they could get all of the information that they wanted or as little information as they wanted whenever they wanted it. And then you also get reports about support, especially with the online chat groups, where people say that it reduced their feelings of isolation and that they had benefits from sharing their views and common interests with other people.

While a number of people support this new medium, the experts also identified a number of issues that needed to be addressed as consumer informatics evolves. They also identified options to address these issues. The top three issues dealt with access, cost, and information quality. As far as access goes, 60 percent of homes don't have computers, and 6 percent lack telephones, although, of course, people can access the technology outside of their homes.

Rural populations and people with personal handicaps or special needs could also find problems with access. The option that was mentioned here and actually the option that was mentioned most often by the experts for all of the issues was public and private sector partnerships.

And they have been shown to address the issue of access. There's an example in our report about the New Jersey project, where public and private sector funds and resources from universities provided computer access to a community where people were not really computer literate.

As far as the cost is concerned, consumers could incur costs for software or online services and even with the low end of technology in going outside their homes, could incur some transportation costs in that regard. Developers also could incur costs, of course, the highest cost being usually for the most complex types of systems.

We found a range—although a lot of the cost information is proprietary—of systems that cost very little to up to $20 million. And at the high end, systems could cost about $1.5 million to maintain. But, you're talking about a very large staff of medical professionals

and an extremely large data base that they're using to answer questions for people.

The options here were also public and private sector partnerships. Demonstrated benefits will really be the thing that's going to drive investors. If people are realizing that they can get benefits out of this, you're going to get more investment in this area.

And then finally, information quality revolves around data being either incomplete, inaccurate, outdated, or biased. And options that were presented there would be one, to educate consumers to use more than one source for their information and then quite naturally, that they should work in concert with their physicians. Health care informatics is not supposed to take the place of your visit with your physician. It's really supposed to enhance that interaction.

Other issues that the experts reported included security and privacy and copyright issues, systems development issues, and the potential for information overload—since we're getting a lot of information anyway—and computer literacy.

Federal, State, and local governments are all actively involved in informatics in varying degrees. At the Federal level, HHS is starting with plans now for greater coordination and collaboration. And that's a really good first step. In our study, we found that a number of Federal agencies are already involved in consumer informatics. What will be needed in the future is more information on collectively what the Government is investing in this technology and what we're getting out of it for that investment. Recently, there has been legislation passed for information technology that really requires that we know what our investments are and what the return on investments will be.

In closing, then, I would say that informatics is a new and evolving field. Most of the projects that we reviewed were very young, under 2 years old, and in very early stages of development. More will need to be done to identify the full benefits, and that's something that we'll have to watch over time. We will also need to address the issues that have been raised by the experts to ensure that consumers get the best health care information possible.

So with that, I'll conclude. And we'll be glad to take questions whenever you have them for us.

[The prepared statement of Ms. Taylor follows:]

Mr. Chairman and Members of the Subcommittee:

We are pleased to be here this morning to help the Subcommittee explore how technology is being used to make health care information more available to individuals. Our discussion today is based on our recent survey of what is called *consumer health informatics*--the use of modern computers and telecommunications to help consumers obtain needed health information. In conducting extensive interviews with 80 experts in the field, we identified 78 informatics projects and obtained a wealth of information on

- the demand for health information and the increasing capabilities of technology,
- the emergence of consumer health informatics,
- reported potential cost savings and other benefits,
- experts' views on issues that need to be addressed in this area, and
- present government involvement and future plans.

Information was also obtained at a conference we sponsored here in Washington last winter, at which 12 of the experts in consumer health informatics discussed their views in more detail. In addition, we received responses to our on-line survey from about 100 Internet users. Several of the experts we interviewed will also testify this morning. Our report on this subject is being released today.[1]

GROWING DEMAND, TECHNOLOGICAL CAPABILITY

Today's consumers are demanding more--and more detailed--health information, and are becoming more active in making medical and lifestyle decisions that affect them. The demand for health information has climbed steadily in the past 5-10 years. In the early 1990s, for example, mail inquiries to the Public Health Service's information clearinghouses rose by over 40 percent, and telephone inquiries more than doubled. Public libraries reported in 1994 that 10 percent of all reference questions were health-related, accounting for about 52 million inquiries annually. 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

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[1]Consumer Health Informatics: Emerging Issues (GAO/AIMD-96-86, July 26, 1996).

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.[2]

The need for information is particularly apparent in self-care situations, for example when dealing with one's own minor injury or illness. About 80 percent of all health care involves problems treated at home, according to the president of *Healthwise, Inc.*, a nonprofit center for health care promotion and self-care research and development. Effective management of these problems can prevent the illness or injury from progressing to the point of needing professional intervention. However, consumers' self-treatment must follow the correct self-diagnosis or benefits from automated dissemination of information could be negated and overall health could be harmed.

The increasing demand for health information has driven the development of consumer health informatics systems. In fact, a number of informatics systems were developed by individuals who were frustrated by their inability to find needed information about their own health conditions or those of family members or friends. Several hundred informatics systems--using a range of technologies, from telephones to interactive on-line systems--have been developed in the past decade alone. Over half of the projects we identified were in operation for 2 years or less, or were still in the very early stages of development.

Advances in technology also make access to consumer health information easier, responding to this increasing consumer demand. In 1995, as reported by the Council on Competitiveness, 37 percent of U.S. households had computers; that number was expected to reach 40 percent by the beginning of 1996. The use of technology in schools is also on the rise. According to Quality Data, Inc., the number of computers in the nation's classrooms has grown steadily just in the past few years, reaching about 4.1 million for the 1994-1995 school year. (In contrast, about 2.3 million computers were in our nation's classrooms in the 1991-1992 school year.) Growth has likewise been rapid in the use of the Internet and commercial on-line computer services. The Congressional Research Service has called the Internet "the fastest growing communications medium in history." The number of Internet users has doubled in size yearly since 1988; between 1993 and 1994 that number rose from 15 million to 30 million people.

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

CONSUMER HEALTH INFORMATICS: WHAT IS IT?

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. 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 supports consumers' ability to obtain health-related information through three general types of systems--those that simply *provide* information (one-way communication), those that *tailor* specific information to a user's unique situation (customized information), and those that allow users to *communicate* and *interact* either with health care providers or other users (two-way communication). I'd like to offer some examples of each of these three general types of systems that are being used in informatics today.

First, examples of *providing* information in one direction include on-line health-related articles, and computer software containing health encyclopedias or specific simple medical instructions, such as how to inject insulin; telephone-based systems that can be automatically connected to databases to call individuals with appointment reminders also fall into this category. Second, *tailoring* specific lifestyle recommendations aimed at improving one's health can be accomplished with automated systems that request information from the consumer--via a questionnaire dealing with current health habits (such as exercise or smoking) and individual and family health history, for example. Information obtained in this way can then be analyzed, scored according to a set standard, and fed back to the user in the form of recommendations for improved health management. Finally, *interactive* communication is available through on-line discussion groups, which offer the chance for those seeking information on certain health topics or concerns to communicate with other users or a physician or other health care provider.

Systems vary a great deal in terms of the technology employed, costs, and sponsors. The kinds of technologies used in the 78 projects we surveyed included (1) telephones and voice systems; (2) computers, software, and on-line services; and (3) interactive televisions and videotape. (Attachment 1 at the end of this statement provides a sample showing the range of projects included in our review.)

The systems costs we were able to identify ranged from very little to $20 million to develop, and maintenance costs at the high end were up to $1.5 million

annually (most cost information was proprietary). One factor affecting cost is whether existing equipment and personnel resources can be utilized. According to an expert from the University of Montana, a low-cost, Internet-type system was developed by students there as a class project, with the university providing the equipment. More complex systems that permit user interaction are usually among the most expensive. For example, *Access Health, Inc.*, contracts with insurers, managed care programs, and employers to provide advice on illness prevention, disease management, and general health information to their enrollees and employees. The company employs close to 500 people, including nurses and technical support personnel; it reports that it has spent about $20 million on systems development over the last 7 years.

REPORTED POTENTIAL COST SAVINGS AND OTHER ADVANTAGES

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

The *Shared Decision-making* system, an interactive video program, was developed to help patients participate in treatment decisions; evaluators have also reported potential cost savings. According to its developer, the system helps educate the consumer, allowing patients and doctors to function together as a team. An evaluation of one program in this system--dealing with noncancerous prostate enlargement--found a 40-percent drop in elective surgery rates. According to the Agency for Health Care Policy and Research, potential cost savings could be substantial, as this is the second most common surgical procedure performed in the Medicare population.

Cleveland's *ComputerLink*--developed to help support Alzheimer's caregivers by reducing their feelings of isolation--can also help save money, according to researchers at Case Western Reserve University, where it was developed. This is because when caregivers are provided access to such systems and other community-based services, according to the researchers, they tend to need fewer traditional health services, potentially saving taxpayers thousands of dollars.

Other advantages cited by developers and system users include

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

In response to our on-line survey of Internet consumers, we found that consumers value support groups for many different reasons. One Internet user said he gains support and understanding from his on-line friends, who know exactly what his disease--Chronic Fatigue Syndrome--is like. Another Internet user said she obtains information electronically that she cannot easily get from other sources about what she called "the true facts from real people living the nightmare of ovarian cancer." Similarly, a homebound caregiver of an Alzheimer's patient described *ComputerLink* as her "lifeline to sanity." Finally, an individual said he gained "immense benefit" from hearing of the experiences of fellow prostate-cancer sufferers, adding his belief that "accessing this material saved my life."

Informatics systems do not and cannot replace visits with physicians; they can, however, make such encounters more productive, for both doctor and patient. Such systems can also prepare doctors to more effectively treat certain patients. For example, doctors were able to diagnose alcoholism with the help of a pre-visit questionnaire because patients tended to be more candid with the computer, which many see as "nonjudgmental." Specifically, in the case of one patient, doctors' notes indicated that the patient "uses alcohol socially"; in contrast, the computer found that the patient had monthly blackouts. Likewise, 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.

While it is not difficult to find consumers and groups who endorse this technology, there are--in the opinions of the experts we interviewed--several issues raised by the rapid growth of informatics, issues that need to be resolved in the coming years.

EXPERTS IDENTIFY ISSUES AND OPTIONS

In survey interviews and at our conference last winter, the experts identified specific issues that will need to be addressed concerning the future development of consumer health informatics, and options for addressing them. The three issues identified as most significant were *access, cost,* and *information quality.* The other five issues raised dealt with *security and privacy, computer literacy, copyright, systems development,* and *consumer information overload.* (Attachment 2 shows the experts' views on the significance of these issues.)

Some health informatics systems are available only to those with available computers, modems, and telephones, which raises the issue considered central to many experts: *access.* About 60 percent of U.S. households lack computers,[3] and at least 6 percent lack telephones.[4] Other identified issues involving access include physical barriers, such as those affecting residents of remote or rural areas, and those affecting individuals dealing with physical handicaps. The next issue, *cost,* was seen as affecting the consumer's use of informatics in terms of expenses associated with purchasing software, fees for using on-line services and, for some, transportation costs to a library or other public source of information. The costs of developing informatics systems were also important to the experts: these issues included how much funding is needed, where funding comes from, and the cost of keeping up-to-date with changes in technology.

Information quality was also seen as a very significant issue because the information in informatics systems could be incomplete, inaccurate, or outdated. According to one expert, CD-ROMs[5] in use with current dates could in reality be based on much earlier, out-of-date research. Also identified was the potential for biased information that may have been developed by a person or organization with a vested interest. Another risk is that consumers could take information out of context or misapply it to their own medical situations. If they were to act on

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[3]Council on Competitiveness, Highway to Health, p. 34.

[4]Falling 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, table 1.

[5]An acronym for *compact disc read-only memory.* CD-ROMs provide rapid, flexible searching of large volumes of data through an optical scanning mechanism that uses a high-intensity light source, such as a laser.

such information without first checking with a qualified medical professional, harmful health consequences could result.

Experts discussed several options for addressing these issues, ranging from applying broad practices to following more specific suggestions. One solution, establishing public- and private-sector partnerships addresses all three issues, especially access. To illustrate: the Newark (N.J.) Public Schools joined with the University of Medicine and Dentistry of New Jersey and a private, nonprofit corporation to provide technology to people lacking access to computers. In addition to using their own resources, in 1994 and 1995, this group was awarded a total of over $200,000 in federal grants. Public- and private-sector leaders noted that the project was an effective approach for ensuring access, and one that could be replicated in other communities.

Experts also 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. Specific suggestions were also provided to address the quality issue. Peer reviews of informatics systems could help ensure quality, or a consortium of experts in a field could be used, involving government and private-sector representation, to establish quality guidelines. The experts also suggested that ways could be found to notify consumers if information is from an unknown source.

Five other issues were seen as somewhat less critical but still needing attention. *Security and privacy* were seen as important, particularly with on-line networks, where consumers may wish to share personal information anonymously. Further, experts felt that while *copyright* laws protect the proprietary nature of systems so that others will not be able to unfairly reap the rewards that rightfully belong to developers, at the same time copyright restrictions can slow the immediate availability of information to the consumer.

In the area of *systems development*, the experts noted issues with compatibility, infrastructure, and 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 or additional hardware. Further, no nationwide infrastructure exists to link information from hospitals, clinics, and physicians' offices, making it difficult to share critical health-related and patient information. And standardization refers to the computer file formats in which patients' health data are stored; various providers use different information systems, further hindering data-sharing.

Finally, *information overload* and *computer literacy* were identified as issues related to the consumer. Mr. Chairman, we are a nation with a wealth of information--and on-line information contributes to this situation. Experts indicated that on-line information could overwhelm the consumer and provide him or her with too much technical information to comfortably handle. Most experts also felt that although systems are becoming more user-friendly, some people still fear computers and other technologies.

Experts also noted specific options for addressing these issues. Sound systems development practices, along with helping ensure that a project is well-designed, can also significantly help safeguard the data. Carefully assessing and identifying user needs will also help develop a system that is user-friendly and accommodates the target users' needs, which can increase consumers' comfort levels with using new technology.

PRESENT GOVERNMENT INVOLVEMENT AND FUTURE PLANS

The federal government in general--and the Department of Health and Human Services (HHS) in particular--are actively involved in consumer health informatics. This involvement takes the form of project development and testing, providing sources of consumer health information, funding clearinghouses and information centers, and providing grants to organizations that produce informatics systems. (Attachment 3 lists a sample of government agencies involved in these activities.)

HHS is charged with controlling disease and improving the health of Americans, and includes consumer information and education among its activities to accomplish this. Many agencies within HHS also have central roles related to consumer health information and services. These include the Health Care Financing Administration (HCFA), the Centers for Disease Control and Prevention, the National Institutes of Health, the Food and Drug Administration, and the Agency for Health Care Policy and Research. Outside of HHS, other agencies having components that deal with health information include the Departments of Agriculture, Commerce, Defense, Energy, and Labor.

As an example of federal involvement, last December HCFA awarded a 1-year grant to the University of Wisconsin's *Comprehensive Health Enhancement Support System (CHESS)*, which supports Medicare patients diagnosed with early-stage breast cancer. Patients choosing to participate are provided with computers in their homes containing the *CHESS* software, which includes detailed health-related articles and the ability to communicate with medical experts and support

groups. The project will review the impact of this system on participants' health and treatment decisions and will help determine the appropriateness of this technology for the Medicare population.

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, and may provide an initial infrastructure that could be used to disseminate consumer information more widely. As an example of local involvement in informatics, Fort Collins, Colorado, has developed its own system, called *FortNet*, providing health and other kinds of information for city residents. Fort Collins contributed over $60,000, to which federal and private contributions were added. A similar project exists in Taos, New Mexico, where the local community enjoys free access to on-line resources that include directories of local health providers. The system is funded by federal, state, and local contributions, including those of the University of New Mexico.

As for the future, HHS has sent a report to the Vice President containing recommendations for federal activities that will enhance the availability of health care information to consumers through the National Health Information Infrastructure, a project that is being jointly undertaken by 14 private companies and nonprofit institutions and the federal government. The National Institute of Standards and Technology has awarded the C. Everett Koop Foundation a grant totaling $30 million--half in government funds and half in matching private funds--to develop the tools needed for such an information network. On the state level, Washington plans to develop an automated system containing clinical information and other medical data; it will be made available to all state residents. Local involvement in consumer health informatics is expected to continue as well. For example, the local communities involved in CHMIS projects plan to provide expanded services over the established networks--additional content areas to serve the health information needs of their consumers.

HHS and other consumer health experts have recognized that federal coordination of government activities in consumer health informatics needs to be improved; while no single, comprehensive inventory of all federal activity exists for this new field, many federal agencies have plans for greater coordination and evaluation of consumer health informatics. For example, HHS' National Institutes of Health plans to consolidate on-line information for its various institutes. Through its Gateway project, HHS is developing a database that is expected to contain

hundreds of publications on health topics. The agency is also involved in developing guidelines for evaluating informatics projects; such an evaluation could be of value in helping the government determine how it is investing in technology in this area.

Mr. Chairman, informatics is a young and emerging field, and systems have grown rapidly in a very short time; they are clearly providing benefits to many. As the use of informatics systems increases, the benefits and issues will become more apparent. Measuring these benefits and determining how we will deal with some of the issues raised by the experts will be necessary to ensure that consumers receive the best information possible.

This concludes my prepared statement. I would be happy to respond to any questions you or other members of the Subcommittee may have at this time.

Attachment 1

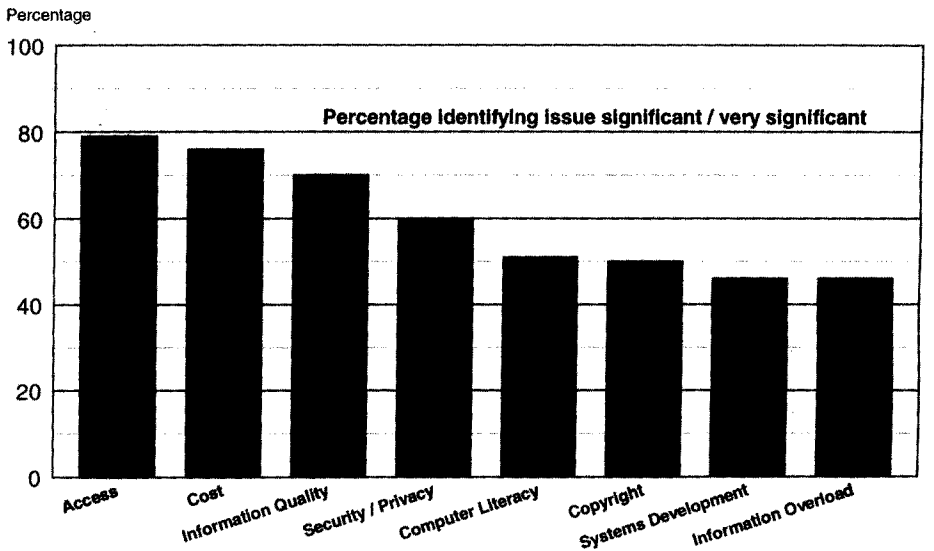
Sample of Informatics Projects by Location, Description, Target Users, and Technology Employed

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	System 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.

Attachment 2

Experts' Views on Relative Significance of Consumer Informatics Issues



Source: GAO analysis of 80 experts' views.

Attachment 3

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

Mr. SHAYS. Thank you. We will have questions. Thank you, Ms. Taylor.

Dr. Deering. Or Ms. Deering. I'm sorry. Or Dr. Deering. It says "Ms. Deering" there. We corrected it up here, but——

Ms. DEERING. Thank you very much, Mr. Chairman, and members of the committee. Thank you very much for inviting me here today to share with you the activities of the Department of Health and Human Services in the field of consumer health informatics, which I may from time to time call CHI. In the interest of time, I am going to summarize my written testimony.

Like you, we believe this dynamic field suggests many opportunities for enhancing individual and public health. Americans today are being called on to take increasing responsibility for their own health and that of their families. The decisions they make may also contribute to more appropriate and effective use of our health care system and help raise the overall health status of our communities.

Timely and effective consumer health information delivered through the emerging interactive technologies could be a powerful tool. In my testimony, I'll discuss the steps HHS is taking in several areas: The direct provision of information through these technologies, coordination to improve access to CHI, partnerships with other public and private organizations to extend the reach and impact of CHI, and R&D and evaluation.

I'll end with comments about a continuing concern, how to meet the needs of all populations, especially those who may be doubly disadvantaged with heavier health burdens and less access to technology. I'm basing my remarks on Secretary Shalala's recent report to the Vice President on HHS's activities in this area, and copies of that report have been placed outside and provided to the committee.

Item A, providing on-line access. Again, for a detailed list of specific HHS efforts, I would direct your attention to attachments A and B of the Secretary's report. We also have a demo over here on the side which can walk you through a lot of what we are doing. We're very proud of the diversity and quality of these activities. Their continued growth is a reflection of the creative energy of our individual agencies and our Departmentwide Internet laboratory.

However, this wealth of information brings problems. There's a need for navigational assistance. HHS is working to make it easier for consumers to find the information they need, both internally through its home page and across agencies through electronic linkages and specific CHI development efforts. For example, our HHS home page includes a subpage on consumer information. We have just launched an updated new, improved version of it, which we can also demonstrate for you.

The public can choose easily from a list of popular topics or a list divided alphabetically. These lead to a data base of 1,000 government agencies, national associations, and other organizations providing health information and referrals to the public. This is now maintained by the National Health Information Center, which is an HHS-funded clearinghouse.

In cooperation with our Internet lab, an interagency group led by the Office of Disease Prevention and Health Promotion is developing a prototype electronic gateway to Federal consumer health in-

formation. Oversight is provided by an HHS committee working with public and medical librarians. The prototype gateway is just completing a proof of concept test phase, and based on the results, we will be developing a proposal for further development and implementation and a budget.

The gateway seeks to simplify access to key health materials while alleviating the problems of information overload, duplication, and currency. It will contain both summaries and full text files for hundreds of health publications produced by the U.S. Government. The summary will tell how to contact the sponsoring agency by telephone, mail, or the Internet.

The user can click on the sponsoring agency's Internet address and go directly to that source. And if that source has the material posted online, then they can click further and get all of the information that they have been seeking.

And so the gateway is not trying to limit access to the full range of online information; rather, it's trying to collect a core body of that information which will provide a first stop, and which may, in fact, satisfy the user's needs. But then there will be links outward to additional information.

The next item is enhanced coordination. We work to improve coordination through several channels. Informally, we convene Federal health information and education staff in informal symposia. Five of these sessions have focused on new communication technology. Others focus on shared concerns like reaching specific populations.

We have also cochaired the consumer health information subgroup of the administration's information infrastructure task force and its subgroup on health information and applications. A copy of the white paper on consumer health informatics is also on the table, as is a copy of the chapter from a second white paper of that subcommittee focusing on consumer health information within managed care.

The Department plans to establish an internal CHI work group to help strengthen and coordinate HHS activities. It would include representatives of all agencies with CHI missions, but it would also include representatives from public affairs, information resources and management, and the Internet lab. Representatives from other Federal agencies will be invited to participate.

Item 3, public-private collaboration. In 1994, HHS convened representatives from the public and private sectors to develop a series of national conferences to explore emerging CHI activities and clarify respective roles and responsibilities. The first and second national conferences, called partnerships for networked consumer health information, took place in California in May 1995 and May 1996.

And by the way, we have some real time video of Reed Tuckson, who was one of our keynote speakers, that we can also demo for you. Some of you may remember that Reed Tuckson was the commissioner of health here in the District of Columbia for a few years.

The conferences also provide the context for more indepth analysis of key issues by public-private teams. For example, next year, groups will focus on reaching the underserved, doctor-patient com-

munication, online self-help groups, CHI and managed care, evaluation, and policy issues. Recommendations and reports from these discussions are issued by various partner organizations.

Next item on evaluation. The department is supporting a variety of individual evaluation efforts which are in the written testimony. The Office of the Assistant Secretary for Planning and Evaluation and the Office of Disease Prevention and Health Promotion are jointly sponsoring a science panel on interactive communication and health. The panel includes leading academic researchers in both interactive health applications and instructional technology. I am pleased to say that Dr. Dave Gustafson is on that panel. He's a good colleague.

The panel itself will not evaluate specific applications or technologies, but it will try to develop a framework that could be the basis for a research agenda that would help guide not only HHS but academic and business communities, as well.

Last item, populations with special needs. HHS is always concerned about vulnerable populations who are most at risk for illness and premature death. In order to reach these and other populations more effectively, we must maintain and strengthen our other communication efforts, including outreach through community organizations and libraries.

I would like to close by saying that this vision of a ubiquitous consumer health network could become a nightmare of tangled links and overwhelming content, as new providers rush onto the Internet. The Federal interest is to preserve both the diversity and quality of information, while enhancing the likelihood that users can actually find what they need when they need it and in a manner that suits them. Thank you very much.

[The prepared statement of Ms. Deering follows:]

Testimony of Mary Jo Deering, Ph.D.
Director, Health Communication and Telehealth
Office of Disease Prevention and Health Promotion
U.S. Department of Health and Human Services

BEFORE THE
HOUSE GOVERNMENT AND OVERSIGHT SUBCOMMITTEE ON HUMAN RESOURCES AND INTERGOVERNMENTAL AFFAIRS

July 26, 1996

CONSUMER HEALTH INFORMATICS STATUS REPORT

Mr. Chairman and Members of the Committee:

Thank you for inviting me here today to share with you the activities of the Department of Health and Human Services (HHS) in the field of consumer health informatics (CHI). HHS includes the Administration on Aging, the Administration on Children and Families, the Agency for Health Care Policy and Research, the Agency for Toxic Substances and Disease Registry, the Centers for Disease Control and Prevention, the Food and Drug Administration, the Health Care Financing Administration, the Health Resources and Services Administration, the Indian Health Service, the National Institutes of Health, and the Substance Abuse and Mental Health Services Administration.

Like you, we believe this dynamic field suggests many opportunities for enhancing individual and public health. Americans today are being called on to take increasing responsibility for their own health and that of their families. The decisions they make may also contribute to more appropriate and effective use of our medical care system and help raise the overall health status of our communities. Timely and effective consumer health information, delivered through the emerging interactive technologies, could be a powerful tool.

In my testimony, I will discuss the steps HHS is taking in several areas: (1) the direct provision of information through these technologies, (2) coordination to improve access to CHI, (3) partnerships with other public and private organizations to extend the reach

and impact of CHI, and (4) R&D and evaluation. I will end with comments about a continuing concern: how to meet the needs of all populations, especially those who may be doubly disadvantaged with heavier health burdens and less access to technology.

I am basing my remarks on Secretary Shalala's recent report to Vice President Gore on HHS' activities in consumer health informatics. Copies of this document have been submitted to the committee and are available on the table [in the rear].

Providing Online Access to Consumer Health Information.

For detailed lists of specific HHS efforts, I would direct your attention to attachments A and B of the Secretary's report. We are proud of the diversity and quality of these activities. Their continued growth is a reflection of the creative energy of our individual agencies and our department-wide Internet Laboratory. Let me highlight just a few of these activities.

- Among its many electronic activities, the Agency for Health Care Policy and Research has a full-text retrieval system, developed with the National Library of Medicine, that provide free electronic access to their clinical practice guidelines. Most materials can be ordered online through AHCPR's electronic ordering feature.

- The Centers for Disease Control and Prevention offers travelers information and reports on prevention recommendations.

- Individual institutes at the National Institutes of Health have posted publications and other material derived from their wide array of research activities. Collectively, NIH is assembling a set of popular NIH consumer health materials to provide through a single point of entry.

- The National Library of Medicine recently launched Internet Grateful Med, an easy-to-use application for searching the vast bibliographic database of NLM by keywords.

However, this wealth of information brings problems. There is a need for navigational assistance. HHS is working to make it easier for consumers to find the information they need both internally, through its home page, and across agencies, through electronic linkages and specific CHI development efforts. For example:

- The HHS Home Page includes a sub-page on Consumer Information. As mentioned in the Secretary's report, we have been working to improve this. The new page was just launched, and I have brought examples of the new HHS Consumer Information page. The public can easily choose subjects from a list of popular topics or a complete list divided into alphabetical sections. These lead to a database of 1,000 government agencies, national associations, and other organizations providing health information and referrals to the public that is now maintained by the National Health Information Center (NHIC), an HHS-funded clearinghouse. It includes all our own HHS information sources.

- In cooperation with the Internet Lab, an interagency group led by the Office of Disease Prevention and Health Promotion is now developing a prototype electronic *Gateway to Federal Consumer Health Information.* Oversight is provided by an HHS committee, working with public and medical librarians. The prototype *Gateway* is just completing a "proof of concept" test phase. Based on the results, a proposal for further development and a budget will be prepared.

The *Gateway* seeks to simplify access to key health materials while alleviating the problems of "information overload," duplication, and currency. It will contain both summaries and full-text files for hundreds of health publications produced by the U.S. Government. The summary also tells how to contact the sponsoring agency--by telephone, mail, or the Internet--to order a printed copy of the publication or get help in locating more in-depth information on the topic. The user can "click" on the sponsoring agency's Internet address and go directly to that source. The *Gateway* does not seek to limit access to the full range of online information. On the contrary, it proposes to provide a "first stop" which may in fact satisfy the user's needs, with links outward to related Federal sites.

Enhanced Coordination

Many HHS agencies and other Federal agencies provide consumer health information. While each has a specific information mandate, we are often addressing the same audiences or providing information about issues that cut across agencies. HHS' goal has therefore been to introduce agencies to each other--so that they can know what each other is doing--and to new approaches--so they can do it better and more efficiently.

Coordination has been advanced through several channels. Federal health information and education staff have been convened in informal meetings and symposia for nearly

eight years. Five of these sessions have focused on new communication technology; others focus on shared concerns like reaching specific populations. HHS staff have co-chaired the Consumer Health Information subgroup of the Information Infrastructure Task Force's Health Information and Applications Work Group (HIAWG) since its inception in April 1994. A copy of that group's White Paper was attached to the Secretary's report. In addition, HHS chairs the steering committee for the national conferences, *Partnerships for Networked Consumer Health Information*, which I will discuss shortly. Representatives from other Federal agencies and private entities sit on that committee.

The Department plans to establish an internal CHI workgroup to help strengthen and coordinate HHS activities, building on core staff from all three of the above efforts. The workgroup will include representatives of all HHS agencies and offices with CHI missions, along with representatives from Public Affairs and Information Resources Management, and the Internet Lab. Representatives from other Federal agencies will also be invited to participate. The workgroup's responsibilities could include oversight of the HHS consumer health information home page and the Gateway project. It could also take the lead in identifying issues and opportunities for improving CHI activities across Federal agencies and with the private sector.

Public-Private Collaboration: Partnerships for Networked Consumer Health Information

In 1994, HHS convened representatives from the public and private sectors to develop a series of national conferences to explore emerging CHI activities and clarify respective roles and responsibilities. The first and second national conferences, *Partnerships for Networked Consumer Health Information*, took place in California in May 1995 and May 1996. The third conference will be held in Washington DC in April 1997. The conferences also provide the context for more in-depth analysis of key issues by public-private teams. These have included intellectual property, consumer health information demand and delivery, promoting the quality and integrity of online information, cost-effectiveness, universal access, and health information community networks. Next year, groups will focus on reaching the underserved, doctor-patient communication, online self-help groups, CHI in managed care, evaluation, and policy issues. Recommendations and reports from these discussions are issued by various partner organizations.

HHS agencies are working directly with libraries and community networks, and also with private entities like IBM's online Health Village project, America OnLine, and

America's Housecall Network to facilitate the inclusion of HHS materials and information into these services.

Evaluation and R&D

Recognizing a need to develop the knowledge base for interactive CHI, the department is supporting a variety of evaluation efforts. The Agency for Health Care Policy and Research has funded assessments of some of the leading research-based applications. The National Cancer Institute's Small Business Innovation Research (SBIR) grants have supported the initial R&D for interactive cancer prevention projects such as nutrition education programs.

The HHS Office of the Assistant Secretary for Planning and Evaluation and the Office of Disease Prevention and Health Promotion are jointly sponsoring a Science Panel on Interactive Communication and Health (SciPICH). The panel includes leading academic researchers in both interactive health applications and instructional technology. The panel itself will not evaluate specific applications or technologies. Instead, it will identify evaluation metrics likely to have the greatest predictive power for judging effectiveness as well as those most relevant for public policy interests. The panel's work will provide the basis for a research agenda that can help guide the efforts not only of HHS agencies but the academic and business communities as well.

Populations With Special Needs

HHS is especially concerned about vulnerable populations, who are most at risk for illness and premature death and are likely to lag behind in access to technology. These include people with special literacy or language needs, and also those with disabilities. In order to reach these and other populations more effectively, we must maintain and strengthen other communication efforts, including outreach through channels like community organizations and libraries. We need to think creatively about reaching them where they live and work. We must make it easy for these groups to stay connected to us by telephone or by adapting our electronic access.

CONCLUSION

The vision of a ubiquitous network linking individuals to health information that is vital for themselves and their families may become a nightmare of tangled links and overwhelming content as new CHI providers (public and private) rush onto the

Internet. The Federal interest is to preserve both the diversity and quality of information while enhancing the likelihood that users can actually find what they need, when they need it, and in a manner that suits them.

As we look forward to the opportunities for health improvement that this technology appears to promise, we should all remember that origins of health-related behavior are pretty complex. In the 32 years since the first Surgeon General's report told us that smoking is harmful, we have learned a lot about how to help people move from knowledge to action. The new interactive technologies may be more powerful if we make sure to incorporate this knowledge. We have also learned that it is unproductive to target a mythical "John Q. Public" as some isolated individual. We know we must reach people as members of families and communities, as patients and caregivers. We must build on all our experience with health communication to harness the potential of consumer health informatics.

Attachment to Doering test.

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

JUL 18 1996

MEMORANDUM TO THE VICE PRESIDENT

SUBJECT: Status Report on Enhanced Health Information for Consumers

I am pleased to forward to you our status report on HHS efforts to promote enhanced health information for consumers through applications of the National Information Infrastructure (NII). In your memorandum of March 8, 1995, you asked us to focus on four areas of health applications in the NII- data standards, privacy, telemedicine, and enhanced health information for consumers - and to report back to you on progress. You noted that HHS already had significant work underway in all of these areas, and you asked us to consolidate the ongoing HHS efforts into a coherent strategy coordinated both with other agencies and with private sector and State roles to achieve more effective use of the NII for health and health care.

In our status report to you in April, we outlined a variety of internal and interagency efforts and accomplishments in the areas of data standards, privacy and telemedicine, and indicated that we had already made significant progress. In the attached report, we describe progress in the area of enhanced health information for consumers.

Individuals, providers and governments all share an interest in informed and empowered consumers who can participate responsibly in maintaining their health and managing their health care. To that end, HHS supports numerous consumer health information activities, and is increasingly turning to opportunities afforded by the NII. HHS has always been a leader in this area, and is building on a variety of existing efforts while identifying new opportunities for enhanced consumer health information. Developments are occurring at a very rapid pace.

The attached status report was prepared under the auspices of the HHS Data Council. Following a statement of principles relating to enhanced health information for consumers, the report outlines a variety of current HHS and interagency accomplishments as well as future plans in the following areas:

- Collaborative HHS Activities to Improve Online Access to Consumer Health Information
- Enhanced Federal Coordination
- Public-Private Collaboration

Page 2 - The Vice President

- Policy Development
- Research, Development and Evaluation, and
- Consumer Health Information Needs of Special Populations

The report also includes a selected inventory of enhanced consumer health information activities of HHS and other federal agencies.

We hope that you will find the report informative, and we would be pleased to discuss any of these activities and plans with you.

Donna E. Shalala

Attachment:
Status Report: Enhanced Health Information for Consumers

CONSUMER HEALTH INFORMATION: STATUS REPORT

In his memorandum to Secretary Shalala of March 8, 1995, Vice President Gore asked the Department of Health and Human Services (HHS) to develop recommendations for federal activities for providing enhanced consumer health information (CHI) through the national information infrastructure (NII). In response, the department is building on existing efforts and identifying new opportunities in online access, coordination, public-private partnerships, policy leadership, R&D and evaluation, and special population projects. These efforts and proposals are based on the following principles:

- The long-term goal is universal access to health information at the "point of need." The individual at home at a personal computer wanting information about healthy behaviors, a patient in a clinic needing information about treatment options, a blind person needing information about services, the newcomer in the community looking for information in the public library--all of these should be able to find what they need, when they need it, electronically.

- HHS is especially concerned about vulnerable populations, who are most at risk for illness and premature death and are likely to lag behind in access to technology. In order to reach these and other populations more effectively, the Department must partner with other Federal agencies and State and local health departments, and encourage private sector organizations and companies to address these groups as well.

- Cooperation and public-private partnerships should guide these efforts. Federal resources are limited. Voluntary health agencies, health care providers and payors, and commercial information services are all major stakeholders in the CHI endeavor. Their respective roles need to be clarified. In order to ensure efficient public expenditure, Federal agencies should partner with the private sector to facilitate innovation and development. Care should be taken to preserve the government's reputation for producing unbiased consumer health information.

- The results must be practical, cost-effective, and flexible. The NII and its applications are evolving rapidly. We must balance advanced technological solutions with actual customer needs and available resources.

COLLABORATIVE ACTIVITIES TO IMPROVE ONLINE ACCESS

There is a great deal occurring throughout the Federal Government to provide electronic access to information for Americans. Attachment A lists some of these ongoing activities sponsored by individual Federal agencies and offices. On March 27, the HHS Internet Laboratory, part of the department's Continuous Improvement Program, sponsored the "HHS Net '96" showcase, which highlighted many of the Department's innovative online products and services. (See Attachment B.) The National Library of Medicine recently launched Internet Grateful Med, an easy-to-use application for searching the vast bibliographic database of NLM.

However, this wealth of information brings problems. Consumers frequently complain about the difficulty of navigating through myriad collections to find information about a given problem. They have difficulty getting directly to full-text publications. Their searches often turn up information that is redundant, conflicting, or out of date. As the demand for and supply of electronic health information grow, these problems will increase. There is a need for navigational assistance. Simplifying access to the health information that is already being provided by many different Federal agencies will enhance its availability and use, and represents a useful and concrete service.

HHS is working to make it easier for consumers to find the information they need both internally, through its home page, and across agencies, through electronic linkages and specific CHI development efforts.

The HHS Home Page. To facilitate coordinated access to HHS information resources, the Internet Lab developed the HHS Home Page. It includes a sub-page on Consumer Information.

The current HHS Consumer Information web pages present good resources on a limited number of topics. However, HHS is a large department with 10 operating divisions, and resources on any given topic may be held by several different divisions, making the task of locating them all a time-consuming one. In order to increase the numbers of both resources and topics presented on the central HHS web page, simplify access for the public, provide sites offering information on multiple topics in the most flexible way, and maintain this information in an efficient way, HHS is developing a database of its Internet resources and classifying those resources according to a standard thesaurus of subject terms.

The public can easily choose subjects from a popular topics list or a complete list divided into alphabetical sections. A list of resources is presented in response to the selection of a subject; selection of any of these resources accesses the database to

return a summary, a direct URL for Internet access, and related subjects to explore. At this point, selecting the hyperlinked URL will take the user directly to that Internet resource, which can be located at HHS site or at sites operated by HHS contractors (e.g. clearinghouses) or grantees. (See Attachment C)

Future plans. HHS plans to enhance public access to health information across the Government by merging this Internet resource database with a database of full-text consumer publications (under development--described in the Gateway project below), and possibly the database of 1,000 government agencies, national associations, and other organizations providing health information and referrals to the public that is now maintained by the National Health Information Center (NHIC), an HHS-funded clearinghouse. NHIC's web page was recently named a "top 5%" site by Point Survey.

Gateway to Federal Consumer Health Information. In 1995, an interagency project, "Libraries as Gateways to Health Information," identified a core set of CHI materials from nearly 30 clearinghouses and developed a kit for public libraries that included special finding aids for librarians and patrons. In the evaluation of this pilot print project, over 75 percent of the libraries participating desired that the health information be made available in electronic form. In cooperation with the HHS Internet Lab, the interagency group is now developing a prototype electronic *Gateway to Federal Consumer Health Information.* (See Attachment D.) Oversight is provided by an intra-HHS committee, working with public and medical librarians. The prototype Gateway is now undergoing alpha-testing. Based on the results, a proposal for further development and a budget will be prepared.

The Gateway seeks to simplify access to key health materials while alleviating the problems of "information overload," duplication, and currency. It brings together in a single database hundreds of brochures and other publications on dozens of health topics--the newest versions of the most requested publications. Through a keyword search, the user's inquiry will be routed through all the publications in the database (not just those of one agency at a time). The Gateway will contain both summaries and full-text files for hundreds of health publications produced by the U.S. Government. Each summary gives a brief description of the publication to help the user decide if (s)he wants the information; each is linked to the full-text files that can be downloaded. The summary also tells how to contact the sponsoring agency--by telephone, mail, or the Internet--to order a printed copy of the publication or get help in locating more in-depth information on the topic.

The Gateway does not seek to limit access to the full range of online information. On the contrary, it proposes to provide a "first stop" which may in fact satisfy the user's needs, with links outward to related Federal sites. The project will assemble a core set of material in digital form and develop an interface that will help a person access a reasonable volume of text materials. Through links to specific sites, the user seeking more information can access as much or as little as (s)he desires.

Future plans. While the prototype contains a limited number of HHS publications, the Gateway could be expanded to include a much wider representation of HHS material and key publications from all U.S. Governments departments and agencies. This unified core collection of Federal materials could be made available through the HHS home page and the home pages of all HHS divisions and other Federal agencies that have other health information on their sites. Each could customize it or add value for its own audiences. This collection would also be very attractive to private sector consumer health information providers because of its credibility and comprehensiveness. They too could add materials from other sources, including Federal materials not in the Gateway, and add value in other ways for their respective audiences.

The ultimate value of the Gateway will be determined by the scope of its contents on one hand, and by the simplicity of the user interface on the other. Both of these will require significant funding, which could come from public or private sources or from partnerships. A mechanism will be created to identify the most popular, timely, and non-duplicative consumer health materials from Federal agencies. Undoubtedly the first step will be nomination by the sponsoring agencies, who know which of their materials are most valued by their audiences. But selecting, organizing, digitizing, and maintaining the currency of the materials could be done through a contract funded by multiple agencies and guided by an interagency steering committee.

The interface will have to be extremely easy to use if the Gateway is to be helpful to people who have neither experience with database searching nor knowledge of the various terms that may be relevant for their questions. It should seamlessly link the user to full-text materials, the HHS home page database of HHS Internet resources, and the NHIC database of public and private health information and referral resources. In addition, it must be accessible for people with disabilities.

ENHANCED FEDERAL COORDINATION

In addition to simplifying consumers's access to health information, HHS seeks to coordinate activities within HHS and with other Federal agencies. These efforts build on the independent information mandates of various agencies as well as their respective

strengths. But these efforts also recognize that we are often addressing the same audiences or providing information about issues that cut across agencies. The goal has therefore been to introduce agencies to each other--so that they can know what each other is doing-- and to new approaches--so they can do it better and more efficiently. With the development of the NII, there are additional opportunities not only to enhance the individual agency efforts but also link them more effectively.

HHS staff have convened Federal health information and education staff in informal meetings and symposia for nearly eight years. Five of these sessions have focussed on new communication technology. Recently nearly 100 Federal CHI staff learned from OMB about possibilities for promoting the integrity of electronic information products through trademarking and other less restrictive practices; and from the Postal Service about opportunities to participate in the WINGS electronic intergovernmental service delivery project.

HHS staff have co-chaired the Consumer Health Information subgroup of the Information Infrastructure Task Force's Health Information and Applications Work Group (HIAWG) since its inception in April 1994. A list of agencies participating in the HIAWG CHI subgroup is given in Attachment E.

Future Plans. The Department will establish an internal CHI workgroup to help strengthen and coordinate HHS activities, building on core staff from this Status Report's development team, the HIAWG CHI subgroup, and Partnerships steering committee. The workgroup will include representatives of all HHS agencies and offices with CHI missions, along with representatives from Public Affairs and Information Resources Management, and the Internet Lab. Representatives from other Federal agencies will also be invited to participate. The workgroup's key functions could include

- identifying, reviewing, and referring to key leadership any issues that require official action;
- overseeing the HHS consumer health information home page and ensuring its links to other Federal and private sites;
- developing, maintaining, and assessing an online inventory of HHS CHI products and services;
- overseeing the Gateway to Health Information project;
- developing and maintaining a Listserv linking HHS and other Federal staff involved in CHI;
- educating CHI staff about new approaches and opportunities;
- promoting collaborative efforts on cross-cutting issues such as search-engine development, quality and integrity, evaluation, and special populations;

- overseeing the third national Partnerships conference; and
- identifying and promoting opportunities for Federal-State-local and public-private partnerships (for both infrastructure and content issues).

PUBLIC-PRIVATE COLLABORATION: Partnerships for Networked Consumer Health Information

In 1994, HHS convened representatives from the public and private sectors to develop a series of national conferences to explore emerging CHI activities and clarify respective roles and responsibilities. The first and second national conferences, *Partnerships for Networked Consumer Health Information*, took place in California in May 1995 and May 1996. The 1996 conference was co-sponsored by the Robert Wood Johnson Foundation, the Annenberg Center for Health Sciences, and IEEE-USA. A copy of the conference brochures for 1995 and 1996 and a list of organizations represented on the steering committee are provided in Attachment F. The conferences also provide the context for more indepth analysis of key issues by public-private teams. In 1995, studies of consumer health information demand and delivery and intellectual property issues were developed for preliminary discussion at the conference and subsequent publication in the medical information literature. In 1996, small groups assessed issues of quality/integrity, cost-effectiveness, universal access, and health information community networks. Recommendations and reports will subsequently be issued by various partner organizations.

The partnerships conferences also include satellite videoconferencing and a "virtual conference" on the World Wide Web. The conference home page address is http://odphp.osophs.dhhs.gov/confrnce/partnr96/.

HHS agencies are working directly with private entities like IBM's online Health Village project, America OnLine, and America's Housecall Network to facilitate the inclusion of HHS materials and information into these services.

Future Plans. The 1997 Partnerships conference will be held in the Washington D.C. area to facilitate participation by Federal decision-makers. It will identify areas where further recommendations are appropriate and showcase successful collaboration stimulated by previous conferences. As noted above, HHS will explore partnerships with the private sector to enhance access to the *Gateway to Federal Consumer Health Information.*

POLICY DEVELOPMENT

HHS staff authored a major white paper that identifies the key policy issues related to consumer health information and the NII. The *Consumer Health Information White Paper* was developed under the IITF's Health Information and Applications Workgroup (HIAWG--see above). It was circulated in Spring 1995, discussed at the May 1995 Partnerships conference, and is now being reviewed by the IITF's Committee on Applications and Technology. HHS staff have authored two other reports under HIAWG auspices that identify opportunities for CHI within broader health contexts. A third report published by HHS' Public Health Service includes public information and education challenges for the public health community in the information age. All were widely circulated. These reports are referenced in Attachment G, along with the full *Consumer Health Information White Paper.*

HHS staff have contributed information and insights for the CHI sections of two other major policy reports, the OTA report *Bringing Health Care Online: The Role of Information Technologies* (September 1995) and the Council on Competitiveness' *Highway to Health: Transforming U.S. Health Care in the Information Age* (March 1996).

Internally, HHS is developing policy and guidelines for Internet communications. This effort includes references to external communication activities such as CHI, although the latter is not a specific focus on this effort. The final reports will guide HHS leadership and the operating divisions in the development of structures and practices for optimum Internet use.

Future Plans. HHS will continue to track issues in this area and respond as needed: by convening interested parties, preparing white papers or other policy guidance.

EVALUATING ONLINE/INTERACTIVE CHI

Recognizing a need to develop the knowledge base for interactive CHI, the department is supporting a variety of evaluation efforts. The Agency for Health Care Policy and Research has funded assessments of some of the leading research-based applications. Results are being shared through AHCPR's diverse research dissemination channels to further an appreciation of the impact of these applications for specific conditions and populations. The National Cancer Institute's Small Business Innovation Research (SBIR) grants have supported the initial R&D for interactive cancer prevention projects such as nutrition education programs. The HHS Office of the Assistant Secretary for Planning and Evaluation and the Office of Disease Prevention and Health Promotion are jointly sponsoring a Science Panel on Interactive Technology and Health

(SciPICH). The panel includes leading academic researchers in both interactive health applications and instructional technology. The panel itself will not evaluate specific applications or technologies. Instead, it will identify evaluation metrics likely to have the greatest predictive power for judging effectiveness as well as those most relevant for public policy interests.

Future Plans. HHS will convene a meeting of agencies that sponsor evaluation activities to strengthen communication among them and identify gaps and common interests. Agencies should be encouraged to implement R & D and evaluation projects to help clarify the need for and use of consumer health information of all kinds. HHS will assess the value and feasibility of creating an online inventory of evaluation projects to facilitate coordination. The 1997 Partnerships conference will include one track emphasizing evaluation. Building on the work of the HHS Science Panel on Interactive Technology and Health, mentioned above, agencies could develop a research agenda, solicit research, demonstration, and evaluation proposals, encourage new SBIR projects, and undertake selective model projects in partnership with the private sector. This R & D effort could be undertaken at a range of resource levels.

SPECIAL POPULATIONS

For populations with special language or literacy needs, HHS is currently making available online existing publications targeted toward these groups. But it will be important to ensure access to more traditional sources and types of information by those without computers and those with special needs.

Future Plans. Because many of our vulnerable populations still rely on the telephone to obtain health information, we would like to expand our capacity to respond to their calls. The toll-free number of the HHS National Health Information Center will be enhanced through automated response mechanisms, but it will be unable to meet demand for personal service. Other toll-free numbers are also improving their automated response capacity through innovative technology. At the same time, HHS would like to be able to support technical assistance and training to diverse community intermediaries that serve these populations, such as libraries, voluntary organizations, and Historically Black Colleges and Universities. In the absence of new funds for such activities, HHS will encourage agencies to add technology training components to existing community-based grants where appropriate.

CONCLUSION

The vision of a ubiquitous network linking individuals to health information that is vital for themselves and their families may become a nightmare of tangled links and overwhelming content as new CHI providers (public and private) rush onto the Internet. The Federal interest is to preserve both the diversity and quality of information while enhancing the likelihood that users can actually find what they need, when they need it, and in a manner that suits them. And as always, the Federal government will retain a special interest in certain populations, such as the underserved, those at high risk for burdensome health problems, and those, like Medicare beneficiaries, toward whom it has specific obligations. In a time of reduced budgets, HHS will pursue these interests through enhanced coordination and targeted initiatives.

Mr. SHAYS. Thank you very much. What we'll do is we'll start with Mr. Towns. Then we'll go to Mrs. Morella, and then I will ask some questions.

Mr. TOWNS. Thank you very much, Mr. Chairman. Let me begin by first thanking both of you for your testimony.

Ms. Taylor, you testified about the benefits of health informatics. And I agree with you. I think that's very important. But what role should the Federal Government play in this? What do you see maybe as pitfalls?

Ms. TAYLOR. I think a number of the witnesses are also going to comment on this today. Now, a number of experts have views about how they would like to see the Government participate, and quite naturally, the issue of funding did come up. Also, though——

Mr. TOWNS. I figured that. [Laughter.]

Ms. TAYLOR. Also, they said that the Government could help with needed research, and I think Mary Jo referred to some of that. And that's the basic theme, that you really need to do the research in these projects to show what kind of long-term costs and benefits you're going to get from them. They also discussed involvement by the Government in ensuring information quality, which is needed but is really tough to ensure.

Mr. TOWNS. On that note, let me just switch back to you, Ms. Deering. We talked about quality of information. The experts interviewed by the GAO identified quality of information as one of the most important issues to be confronted in this area. What is HHS doing to assure high quality information in the projects that you fund?

Ms. DEERING. Well, there are several things that are being done. First of all, as you know, the information products and services come from the agencies of HHS, and they set, first of all, their own internal standards because most of their information is generated from a research base and then translated into diverse types of material and made available to the public. So the original quality control comes through the scientific work to ensure that the content which is generated is sound.

In terms of what we can do to ensure the soundness of the information once it's out there in this digital world, I would mention that one well-known example is the National Library of Medicine, which has had congressional approval to actually license some of its information products to specifically help ensure the integrity of its data bases. That is another approach. I believe NLM is the only one that has that type of a system in place.

Mr. TOWNS. Let me share with you that when we have these kind of hearings, that sometimes, members get off their frustration. And I want to say that to you before I go into what I'm going into now. I'm concerned, and let me just tell you why I'm concerned. I'm excited, and I'm concerned, so I'm sitting here with mixed emotions that here we are moving forward with this project, and we should move forward with it.

But I can't help from thinking about the poison control centers, that every year, we have to fight and fight and fight to keep them from being closed. Some of them shut down in terms of half of schedule, and they provide some of the same kinds of things that we're talking about here. Now, once we move into this—and I'm

hoping that we will—how do we guard against this kind of nonsense?

Ms. DEERING. I must confess, I don't have the answer to that. And I would be happy to provide it for you. I know that the poison control centers provided an invaluable telephone service, and there's a national network of them.

I know also that HHS has published the phone numbers of the poison control centers in a health hotlines booklet that's put out by the National Library of Medicine in the past. But in terms of the level of funding for the poison control centers, I can't provide you with a direct answer now. I would be happy to try and submit that later for the written record.

Mr. TOWNS. I would like to get that, because every year, we go through this process with them, trying—whether they're going to be open, certain amounts are going to close, and others are going to be open one day—that's very frustrating. But at the same time, we're moving forward. And I think that—I'm just wondering at what point will we have the same kind of problem here if we decide to make a commitment to move forward.

Ms. Taylor, do you want to comment on that?

Ms. TAYLOR. Well, the only thing that I would add is that it goes back to the theme about benefits and reported benefits, making sure that people can talk about what their investment has been and what you're getting out of it. I think that's the only way you can really make a good decision.

Mr. TOWNS. Let me switch to another area. Some people are saying that the big winners in something like this is the health insurance industry, which is fine. I don't have a problem with that. But what are they contributing to the developmental costs to these systems? Are they contributing to the costs?

Ms. DEERING. Which one——

Mr. TOWNS. Both of you.

Ms. TAYLOR. Well, I would say that the insurance companies are definitely investing in this, and I'm sure that they see a benefit in their participation.

But I think one of the things that we noted in our review is that there is a broad level of players and people who are involved in informatics. That includes technology companies, health maintenance organizations, and Federal, State, and local governments. So I think people are participating at equal levels, and people are getting different kinds of benefits out of it.

Ms. DEERING. I would certainly agree with that and point out that in addition to the insurance companies, it's the big HMO's. For example, U.S. Health Care just launched a $25 million consumer health information activity. This was announced in the Post a couple of weeks ago.

Ms. TAYLOR. Yes. I think one thing that I would add there is that a lot of the insurance companies and HMO's are really seeing this as a way for them to decrease their cost, and they're looking at it that way.

Mr. TOWNS. I think that they should definitely make a commitment, no question about it. And I'm happy to hear that some of them have been moving forward in doing that. Let me just sort of close. I see the question light is on.

Mr. SHAYS. I'll give you a little more.

Mr. TOWNS. I can have more time? Thank you very much.

The other part that I'm concerned with is the protection of individual privacy. What is the Government doing to assure that the system it invests in has adequate protection of individual privacy?

Ms. DEERING. Well, right now, you must remember that in terms of what the Federal Government is directly investing in in consumer health informatics, it's spread across agencies, and much of it is in developmental or research phases.

In terms of what we're doing with consumer health information through our direct online systems, we are quite concerned that this wonderful new technology makes it quite possible to not only identify what information an individual is accessing, like age-related information, but it then tells who it was who accessed that information.

We are exploring the implications of that. We know that it could fall under Freedom of Information provisions. Through the work of our Internet laboratory and our information resources management office, we're looking into what steps we can take.

Ms. TAYLOR. Our group, too, has done a lot of work in the automated records area. And security, of course, always comes up as an issue. One of the things we found is that your printed or paper records are not as secure as you would like, as well. So I think that information being online just exacerbates the situation.

I wanted L.J. Latham to add a little bit more on security.

Mr. LATHAM. I think that is a serious problem that is going to be facing the successful implementation of the system, especially as it gets to systems where the individual identifies themself with information. But there's a cost for securing those kinds of information. It is not a technological impossibility.

There are solutions for that. I think that I would say from my experience with different agencies that have tried to implement security at such places, at health care, financing, the administration, and also SSA, it requires a real detailed analysis of just what the risks are to the individuals and then to assess the most effective kinds of controls to put in the systems when they're built and to basically mandate those when the information being transmitted is in serious danger of being intercepted or modified or, in some cases, totally taken, deleted.

So I think there is going to have to be quite an intensive investigation by all concerned to make sure that those security controls are built into any system that is fielded.

Ms. TAYLOR. And I think L.J. brings up a good point, because what we found in our other security work is that you've got to build this stuff in at the beginning, because it's quite costly to try to come in at the end and build in these safeguards. So you really want to make sure you have the planning done up front.

Ms. DEERING. I would like to only add that I think this is one of the many areas where sharing across agencies would be very helpful. This is developing so rapidly, and different pockets of the Government are moving ahead on specific issues. This is one area that really cries out for real good communication across agencies.

Mr. TOWNS. I was just thinking about, how do we arrange to coordinate this and to get all of the players involved or committed in

the same way. And I don't know how we can do that, but I think you're right. I think it has to be done, and I think that we need to start working toward doing that.

Let me just ask this question, then, Mr. Chairman, I yield back. Most of the health information available requires a fair amount of sophistication to understand. How much of the investment in these systems go into interpreting this information for persons with low reading skills or little formal education?

Ms. TAYLOR. The experts also identified computer literacy as an issue. I wanted to point out, though, that not all of these systems involve a computer. For example, I have a family that is very resistant to using answering machines. If my uncle calls and an answering machine picks up, he's not going to leave a message.

So I think education is part of it. I am encouraged, though, because you see so many systems popping up that don't really involve too much advanced technology that scares people. The other thing is, too, systems development. And that was some of the issue that they brought up. What you need to do if you're going to build a system is get a chance to know your user and to make sure that you're designing what the user needs and feels comfortable with to make sure it's going to be successful.

Just to digress for a minute, we have also done some work looking at the health care system over at DOD, and that has been a big success. It has taken them some time. It's called the composite health care information system.

And what they found at the beginning was that the way the computer screens were set up was not user friendly to the physicians. They went back and redid them, and they put the medications in the order that the physicians learn their meds in medical school, for example. They found out that that picked up usage right away.

So it's that type of stuff. You really need to find out what people are comfortable with and in systems talk that's called getting requirements for your system. It's very important to understand the requirements before you get into systems development.

Ms. DEERING. In the health communication area, it's called consumer research. And I'm glad that you mentioned it, because certainly, you have to understand how your particular audience likes to get information. It may be that they're very oral or visual in their natural information patterns. The Federal Government isn't doing anything in interactive television, but there are some big commercial investments being made in interactive TV.

These developers are betting that while not everybody has a computer, 98 percent of the people have TV's and know how to use the remote, that they can, in fact, package health information online over interactive TV.

Mr. TOWNS. Thank you very much, both of you, for your testimony. And, of course, I yield back, Mr. Chairman.

Mr. SHAYS. Thank you, Mr. Towns.

Mrs. Morella.

Mrs. MORELLA. Thanks, Mr. Chairman, for holding today's hearing on consumer health informatics. As the chair of the Subcommittee on Technology, I'm certainly aware of the important and increasing role of technology in providing health information to con-

sumers. As a matter of fact, last year, we had a committee hearing in Montgomery County at the Library of Medicine.

Actually, we had it at the National Institutes of Health with the Library of Medicine participating. We did one on telemedicine, and we have had a number of other meetings on that. And it's particularly nice to have you here, Ms. Taylor, and to see my good friend, Mary Jo Deering, here.

Ms. DEERING. Hello, again.

Mrs. MORELLA. I appreciated the information that you——

Mr. SHAYS. You always seem to know everyone we get for these committees. [Laughter.]

Mrs. MORELLA. I just always say, "We got the creme de la creme of the country" in this region. I'm very lucky.

Questions have been raised about the appropriate Federal role in health informatics, and I'm glad that we're addressing that at this subcommittee hearing today. People access health information through personal computers in their homes, as has been stated, libraries, clinics, hospitals, and the Internet.

Matter of fact, one of the things we did in the telecommunications bill is to try to make sure that we had affordable access provided for schools, libraries, and rural hospitals with that idea in mind. Clearly, health informatics have many benefits. Evidence suggests by using health informatics, people avoid unnecessary medical services, reduce health care costs—so I think that's going to be another factor that's becoming even more important.

People are more comfortable reviewing health information at their own pace in the privacy of their home, and improved informatics have increased the scope and the availability of health care information. Of course, I have a concern that there's a large population that cannot access health informatics because they don't have computers; also, the fact that they are not computer literate.

It's also, therefore, critical that we increase the public-private partnerships. I'm also concerned about the quality, accuracy of the information that they receive, and this is something this committee is addressing. Outdated or inaccurate information could adversely affect important medical decisions.

I'm also—and the question I would ask to begin with is, what about the whole concept of self-treatment and self-diagnosis? I mean, you can have the accurate information that gets out there to individuals, but do they really know how to treat themselves, how to diagnose it, and what is our role in that in helping bring that about? I think both of you probably would like to address it.

Ms. TAYLOR. I think we point out in our report that about 80 percent of all health care situations involve some kind of self-treatment and things that are done at home. And that's why I think the issue is extremely relevant.

And I think it is, as you say, a real caution, Mrs. Morella, in how this information is going to be used. And that's why I would encourage people to use them in concert with their physician or at least try to make sure you connect with a medical provider.

I think there was an example of someone who had seen on a computer screen, or something, information about a liver disease and kind of thought that he had the liver disease and started taking some kind of holistic medicine.

I'm not sure if there were dramatic negative effects, but it's that kind of example that really makes you want to proceed with caution with some of the ways that people are using this to treat themselves. Like I said, it's something that you want to use in concert with people who have the medical experience and the training to know exactly what they're doing.

I have another example, too, about the video programs. I have an uncle now who has been diagnosed with inoperable cancer. And it is true that once you hear the diagnosis, you really don't hear what comes after that.

I think that his doctor gave him a video, and he watched it at home. And because of that, he was better able to ask questions of his doctor. It wasn't that he decided to treat himself for this condition, but he definitely got a better handle on what his options were and got a chance to ask better questions when he made his way back to the doctor.

Ms. DEERING. I guess I'll mention three different approaches to that. The first is from the Federal Government's point of view. We try to make sure that our own information remains intact in as many sources as possible. That is one of the intentions behind the gateway project, that it would be such an attractive package of reputable government information that any commercial service, any online service, free or fee, can pick it up, and at least there will be that foundation of sound information.

Second, we, too, share the concern about not setting up an adversary relation with the doctor. And I'll mention the third area, because the second and third areas we're both addressing through next year's conference, which I'll get to in a minute. And then the third area is looking at these self-care, self-help groups that are functioning online.

Many people would say that those communities out there are doing a lot of the diagnosis and information sharing, as opposed to just an individual accessing a body of information.

And so in those two areas of doctor-patient communication and the online self-help groups, we're going to have special workshops to bring together the people who are actually doing it and to see how—for example, in the case of the online self-help groups, we'll bring them in. We're going to surf the Net to find out who are the people who are really leading these chat groups, and bring them in and talk about how they can find and ensure access to reputable information sources.

Mrs. MORELLA. Very good. Very good. I have other questions to ask, but let me just ask one more, because we're going to be going to vote. You mentioned a conference. Well, also, Dr. Deering, you have the partnership for networked consumer health informatics issued reports from two conferences that were held, and you mentioned that. But what recommendations came from those two conferences?

Ms. DEERING. Well, it's interesting. We did not originally plan to come out with recommendations, because we recognized that this was a brand new field, and we were the very first to bring together not just government, not just researchers, not just the voluntary sector and public health sector, but the commercial developers, the library community.

And so it was experimental. And, in fact, Robert Ward Johnson gave us money just to continue the experimental approach. But the recommendations that came out were very interesting in terms of the role of the Federal Government.

The very first recommendation for the role of the Federal Government was as a convener and facilitator. Certainly second was in terms of a direct provider of funds and research. But I think it's interesting that all the parties recognize that the Government may have a role, but it's as much helping everybody else as it is doing it itself.

Mrs. MORELLA. That is very interesting.

Ms. Taylor, you've mentioned your uncle, who didn't even use one of the recording machines. I love using it to call people, but I hate answering it, if any comes in to me. At any rate, just one final point, if I have a—particularly on a Friday afternoon, when you call people and say, "Just wanted you to know I'm returning your call." [Laughter.]

But in terms of—mention was made of the range of cost. And I'm just wondering, is the cost connected to the quality or how good the system is? I mean, do you have the best systems that are the most costly? What is the difference? Is there?

Ms. TAYLOR. I think in general, the more technology and more sophisticated you get in technology, the higher the cost could be. But I think when you look at these combinations of public and private sector partnerships and also with the universities stepping in, you end up getting some very sophisticated technology at very low cost.

You'll hear about one of those today in some of the demonstrations around here. But that is really how you end up getting a lot of technical sophistication without spending a lot of money. Some of these costs are low because you're using existing resources. You're using computers that are already there. You're using students at universities who are pretty low-cost participants in the development process.

Mrs. MORELLA. I can see more and more companies, employers setting up areas where they have these computers and train their employees how to use it so they can access it during lunch hour or a certain period and that this would enhance morale, productivity, and health and minimize costs. So great potential.

Thanks, Mr. Chairman.

Mr. SHAYS. I thank the gentlelady from Maryland, who knows everyone by their first name.

I had a number of questions. What we're going to do, though, is I'm going to ask you only a few, because we're going to have a vote. Then I'm going to have—Mr. Towns has already left—to get the second panel started. So I'm going to conclude with all of you by asking some questions. Shorter answers would be preferred.

My general sense is that I want the Federal Government involved as little as possible so that we can have the private sector compete and be energized. I really believe that in the end, the better products will come ultimately to fruition. But having said that, where does the Federal Government have to get involved?

Ms. DEERING. No. 1, in providing the content base. The research that we fund provides the basic knowledge base that should con-

tinue to feed the content of all of these applications, and we also have a role in promoting the maintenance of quality at a minimum.

Ms. TAYLOR. I would stress the research, as well. Because if you want to get the private sector to invest, you're going to have to show them returns. And so as much as you can show, the more you'll get——

Mr. SHAYS. It strikes me that another way we need to make sure that this information that is being provided to the general public is not so inaccurate as to cause death and illness. And so the Federal Government would have a role there?

Ms. TAYLOR. I think that quality of health care information is one of the issues. And just like I think we have referred to before, it's better if people are encouraged to use a lot of different sources and not just one.

Mr. SHAYS. In policing this system, who would decide whether information is so inaccurate or is being misused that it would harm individuals, unknowing individuals? Who should decide that?

Ms. TAYLOR. I think we heard about the possibility of consortiums that could be developed; also, peer reviews that could come in and look at the system and determine if the information is so outdated and also potentially dangerous, that maybe it shouldn't be included.

Mr. SHAYS. I'm going to ask the next panel this, as well. The savings from informatics is obviously to the generic health care industry, to the Government, to anyone who would have spent money on health care for a service they didn't need.

But who makes the money? Let me put it this way. Here I'm asking you to give short responses, and I'm asking long questions. What I'm trying to get at is this. Since I believe in a market model, is there money in the system to encourage organizations like this to try to find the most advanced ways to communicate?

Ms. TAYLOR. Sure. I think that technology is the future. I mean, that's kind of the business I'm in, and I really see a lot of money being devoted to all aspects. This one is a little bit newer, and I just think you might not see a lot of investors right now because of that. But I think it's definitely something that could catch on.

Mr. SHAYS. Do you agree with that?

Ms. DEERING. I would also say that the money would not come only from the medical system which would purchase and promote these systems. Many of these developers see this as a direct line to the consumer market, so individual families and consumers would be purchasing or paying for these systems.

Mr. SHAYS. Ed and I were talking about it toward the end of your testimony. I love it when people say, "Even a child can use these systems." And I'm thinking, "Even an adult can use it."

But that's not our problem. I mean, obviously, you have the telephone, you have TV, besides data systems and so on. But how do we deal with Ed's district that may not have the same capability to access information as the Fourth Congressional District in Connecticut, where there might be two or three computers in one home?

Ms. TAYLOR. Yes. I think a lot of those joint partnerships were really trying to get at people who are in underserved areas. And a lot of times, especially when the universities are involved, you

can make sure that people have other avenues. You don't have to have a computer in your home to be able to access online information. You can go to a library, you can go to clinics, you can go to other places. But you're going to have to have incentives too, I think, to encourage people to build those kinds of systems.

Mr. SHAYS. And the knowledge and confidence that you can actually use these systems.

Ms. TAYLOR. Yes.

Mr. SHAYS. So I would think there, again, the Federal Government would have a role.

Ms. TAYLOR. You mean in training people to become more computer literate?

Mr. SHAYS. Training, have the programs in areas that are the most disadvantaged.

Ms. TAYLOR. Yes. I think some of the research——

Mr. SHAYS. But then again, I imagine that if you're talking about health care providers in a certain area, and we're trying to provide information to their clientele within a poor area, it's to their advantage as well to promote and actually fund outreach efforts; is that accurate?

Mr. LATHAM. I think what has to be done, as Mrs. Taylor said before, I think we have to understand what the requirements for this are. And this surely involves knowing the demographics of the various areas that are being served. That all goes into developing what kinds of systems are most effective for what parts of the population.

Mr. SHAYS. Privacy, I am very concerned about it. Mr. McDermott, a Democrat in Congress, has a bill to deal with the whole issue of privacy. This is a gigantic issue here. Would the Federal Government have a role in the privacy issue?

Ms. TAYLOR. I think in the long term, because of some of the integration efforts, privacy is always going to be a topic that's discussed. I think people are very interested in where their health care information goes, especially when we're talking about a lot of sensitive information.

Mr. LATHAM. But I think the Government does have some expertise it can share in this consortium. And so consolidated public-private partnership, I think that we do have some expertise in some of the Federal agencies in knowing what kinds of security and privacy controls are best suited for systems like this.

Mr. SHAYS. I'm going to have to get on my way to vote. But do any of you have a last word?

Ms. Motley, you have been very faithful to your boss here. Do you have any comment that you want to make, any observation?

Ms. MOTLEY. No.

Mr. SHAYS. OK. It's wonderful to have all four of you here. And thank you very much for your testimony.

Ms. DEERING. Thank you very much.

Mr. SHAYS. Take care.

This hearing is recessed, and we'll come back in when Mr. Towns comes back.

[Recess.]

Mr. TOWNS [presiding]. Let me call up the next panel, Dr. Allen Douma, David Gustafson, Kirk Shelley, Dr. Kirk Shelley, and Mr.

Omar Wasow. Everybody come forward. Will all of you stand? It's the longstanding tradition of this committee that we swear everybody in.

[Witnesses sworn.]

Mr. TOWNS. Thank you. Dr. Douma, why don't we start with you?

STATEMENTS OF ALLEN DOUMA, CHIEF EXECUTIVE OFFICER, HEALTH RESPONSEABILITY SYSTEMS; DAVID GUSTAFSON, PROFESSOR OF INDUSTRIAL ENGINEERING AND PREVENTIVE MEDICINE, UNIVERSITY OF WISCONSIN; KIRK SHELLEY, CHIEF MEDICAL DIRECTOR, HERSHEY MEDICAL CENTER; FARROKH ALEMI, ASSOCIATE PROFESSOR OF HEALTH CARE MANAGEMENT, CLEVELAND STATE UNIVERSITY; AND OMAR WASOW, FOUNDER, NEW YORK ONLINE

Dr. DOUMA. Thank you very much. Let me just add that one of the most difficult things in thinking about coming today is trying to distill 20 years of experience into a few minutes. And I much more—in many ways would rather be responsive to your questions. But I would like to make some statements, also.

But one of the things I would like to reflect back on what you said, Mr. Towns, which I think is critically important, and that's the issue of continuing funding for whatever the Federal Government is involved in.

And I think continuing funding of this kind of process will come as a result of the American people understanding the critical importance of what we're talking about and the power of interactive technology in improving their lives, as well as, in fact, saving money, particularly Federal dollars. And if we can working together in the private sector, which is where I am, with the Congress in disseminating that message, I think we'll all be more successful in the long run.

So I want to say good morning, and my name's Allen Douma. And I'm the medical director for Health ResponseAbility Systems. And we produce the Better Health and Medical Network, which is a major portion of health and medical information services on America Online.

And I really hope that in bringing my perspectives today—and they are simply my perspectives—that I can help you in making decisions about how the Federal Government can provide even more effective health care benefits and services while controlling spending, a critical component of what I have to bring today.

I would like to make a few key points. The first one is that empowering people improves their health, well-being, and the use of medical services, while helping to manage medical costs. The second point is that online technology is an extremely valuable tool for empowering people, especially with regard to health and medically related issues. And third, our Federal Government working with the private sector can play a very important role in catalyzing more and better use of online technology, especially for populations that typically do not have access.

Before getting into some specific areas and perhaps if there's time, some recommendations, I would like to provide a little bit of background about the technology but also the importance of empowerment and influencing people.

Actually, I was an engineer who turned physician, and I worked in private practice in rural settings. In fact, I was taking care of about 13,000 people over 2,500 square miles as a solo practitioner. But I eventually ended up working as a medical director for some major corporations and, in your presence, sir, I hate to admit, even an insurance company at one point.

But from that experience, I've learned that good health and good medical care depends primarily on good communications. Online technology is an extraordinarily powerful tool for better health communications. But the technology itself is not new. In fact, 15 years ago when I was on staff at the American Medical Association, we built an interactive online service for physicians.

But it wasn't until the last few years that this technology has really become widely available to the general public, so much so that now, almost 15 million homes have access online technologies. And this is a number that is several times greater than it was just a few years ago.

And, in fact, we think this number is going to perhaps grow even faster, as within the next 6 months or so, it appears that a $400 piece of equipment will attach to your phone, your TV, and put you on-line. This will be particularly advantageous for the elderly population, which has been hesitant, I think, to spend $2,000 to $3,000 on a computer.

There are now already 10 to 20 million people who have access to the Better Health and Medical Network itself. It now reaches into 6 million homes of about 12 million people, and it has over 1.5 million visits per month and hosts over 400 live self-help support groups every month.

Research has shown over the last 30 years that, in fact, empowering people through information and support has a dramatic impact on the quality of their life, the quality of their health, and their use of medical services. This has led to several research projects and projects that I was involved with using phone-based services, which showed as much as a 10 to 12 percent reduction in medical claims costs as a result of these services.

More recently, we completed a survey of over 1,000 people using the Better Health and Medical Network. And over 90 percent—in fact, it's probably over 96 percent—of respondents indicated that use of this service did a number of positive things.

It increased their ability to understand their medical problems and medical treatments and, equally importantly for me and my colleagues, it improved their ability to communicate with their health providers. And over 50 percent indicated the service improved their and their family's health.

At the same time, this group indicated that there was a decrease in unnecessary hospital, emergency room, and doctor visits. Now, this should not be surprising. In particular, I guess, hearing where Mr. Shay is coming from for his approach, it is not surprising because an informed consumer is, in fact, the basic bottom line requirement for a market economy. In fact, if we all remember Economics 101 many, many years ago, it based—the whole premise of our free market model was an informed consumer.

And what this leads to is an efficient delivery of services. And by efficient, let me emphasize, I mean the highest quality service

at the lowest possible cost. In no way is efficiency denigrating quality. But for an informed consumer to exist, they must have the right information at the right time, and they must be able to apply it. And today, we calmly call that person empowered.

So information is not alone. It really requires extra support for the individual to feel comfortable in use of that information. I think this is particularly true for those who are less advantaged, more cowered, I suppose, by the medical care delivery system who need to be particularly empowered to interact with that system.

The online services like the Better Health and Medical Network are more empowering because they can provide information in context and in an environment that encourages each person to evaluate the information, dealing with part of the issue that you folks have raised about how is this information going to be used, as well as they can get incredible human support from people who have the same or similar medical problems. So they're getting the psychological support, as well as the information delivered at the time they need it.

I came prepared to share a number of messages on our message boards. In fact, we received over 500,000 messages to date from American people about the use of online service and the interconnectivity. It's not their academic assessment of it, it's basically saying what their questions, concerns, and problems are. But in light of the time constraint here, I would like to refer to testimony in which there are a number of those there.

Well, the question for you today and the reason I'm here today hopefully is to try to help you to figure out how the Federal Government can actually incorporate this stuff into what you're doing. First of all, I would like to applaud the Federal Government, including this committee, for what it has done, the GAO folks that I worked with who are incredibly gracious and professional, as well as many HHS agencies, and particularly what Mary Jo Deering has been talking about.

But what I'm here to say is that, as much as has been done, a heck of a lot more can be done. And I also would like to, I guess, put forward a key point, is that increasingly, I hope the Federal Government works with and leverages the private sector, not because the Government doesn't have a critical role, but the private sector is going to be spending large amounts of dollars, and we need help from the Government, in fact, in many ways how to direct some of those dollars.

Let me make a couple of suggestions. And again, in my testimony, I have more. But what I would like to say is that when you talk about insurance, that, in fact, the Federal Government is the largest insurance carrier in the world.

As the third party payer for Medicare and influencer of Medicaid, it has the incredible opportunity and, I submit, social responsibility to look at the use of these online technologies through that third party system for which we're all responsible to empower people, especially to empower the elderly, so that they can improve the quality of their life, as well as improve the medical care services they get. And, in fact, research has shown they can decrease costs.

But let me submit, even if the costs don't go down and if the costs—any more than it costs to deliver these services, we will pro-

vide an incredible, incredible support service for the American people for nothing. And I like those numbers, at least.

And so Medicare turns out to be an excellent opportunity for the public and private sector to work together, as we know that more and more of the Medicare is being handled by HMO's and the like.

I would also like to urge the governmental agencies to put greater emphasis on the patient and the consumer. I can select out a few. For example, the FDA could increase access to information and focus on using it wisely as a shift in their emphasis, and that will certainly help the private sector, as well.

And the National Library of Medicine, which is one of the most incredible information developing machines in the universe—and, in fact, we provide Med Line through the Better Health and Medical Network to the consuming public—also can have the opportunity to look more at delivering information directly to the consumer written at the levels in which you were talking about earlier that people can understand.

I think the Government can take a leadership role in helping with the less advantaged. I believe that delivering these services to the less advantaged, whether inner cities, rural area, whether they're—and I say "elderly," less advantaged into in a financial sense, but in the sense of their fear and anxiety about computers, for example—is that the Federal Government can play an incredibly powerful role, again, in leveraging what the private sector can provide.

I would love to see the private sector getting involved in placing in senior citizens homes, in churches, in libraries, in health clinics, whether they're in the inner city or whether in rural areas or, quite frankly, whether in suburbia where a lot of us live in order to be able to provide the access to those who cannot have—those that have the equipment at home or are too intimidated today to actually do it themselves. They need the kind of training that I think the Federal Government can provide.

Another area in which the Government can help—and Mary Jo is already addressing that, to some degree—is encouraging national voluntary health organizations to build areas online. We have actually built seven areas for major national organizations. But quite frankly, the cost benefit for us in the private sector, there are literally thousands of voluntary health organizations, all doing good work. But we can't afford to provide services for every one of them.

And finally, I would like to say is that—back to where I started, sir. If we want to ensure funding and funding not simply to deliver services but funding to deliver the kind of research that we all need to make sure the services are good, what we need to do is to bring the message to the American people.

And I suggest each of you as individuals directly communicating with your constituency, as well as every Federal communications program related to health, has an opportunity, in fact, to bring, I think, the most powerful public health message that I've read to date, and that is empowerment through health information and support improves health and well being, quality of life, and saves money.

In summary, it has already been shown that online technology is an effective tool to empower people to improve their health and

quality of life. However, we have got a long way to go to reach everybody. Working together, we can greatly increase the rate of growth, especially for those that need it the most. We can also help those with special needs.

Although I made some specific suggestions here today and have more to offer at another time—and those who know me know that I've got hours of suggestions to offer—I turn to you to best determine the ways for our Government to deliver on the promise. However, I would like to urge you to move forward very quickly and to leverage the dynamic growth that is happening now in the private sector. I thank you very much.

[The prepared statement of Dr. Douma follows:]

Health Online - Congressional Testimony
July 26, 1996
Allen Douma, MD

Good morning, my name is Allen Douma. I'm Medical Director for Health ResponseAbility Systems, Inc. We have developed and provide the Better Health & Medical Network -- the major portion of the health & medical information services provided on America Online.

I want to thank you for asking me to discuss the use of online technologies to improve the health of individuals as well as support our federal government's health programs. I hope that hearing my perspective will help you in making decisions about how the federal government can provide even more effective health care benefits and services while controlling spending.

I would like to make a few key points today. First, empowering people improves their health, well being and use of medical services while helping to manage medical costs. Second, online technology is an extremely valuable tool for empowering people, especially with regard to health and medically related issues. And third, our federal government, working with the private sector, can play a very important role in catalyzing more and better use of online technology, especially for populations that typically do not have access.

But before talking about specific areas, I'd like to provide some important background information about how and why online technology is such a powerful tool that can simultaneously enhance quality of life for everyone while saving money.

As an engineer turned physician, I've worked as a private practitioner in rural settings and as a medical director for major corporations. From that experience, I've learned that good health and medical care depends primarily on good communications. Online technology is an extraordinarily powerful tool for better health communications.

The technology itself is not new. While on staff at the American Medical Association 15 years ago, we developed an online service for physicians. However, only in the last few years has this technology become widely available to the general public.

Almost 15 million homes now have access to online communities where people are getting health information and support for themselves and their loved ones. This is several times the number of a few years ago. And many of us predict that online services will grow even faster in the next few years, especially in older populations, as online access hardware only costs $400.

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It's estimated that already ten to twenty million people have visited the largest of these online health communities -- Better Health & Medical Network, run by Health ResponseAbility Systems on America Online. It now reaches into six million homes, has over 1.5 million visits per month and hosts over 400 live self-help support groups every month.

For more than thirty years, research studies have shown that programs that educate and empower patients to be informed decision makers can improve their health and improve the use of medical services.

More recently, studies have shown that health communication programs using print and telephone services improve a person's sense of well being while reducing the use of unnecessary medical services. Some of these programs have saved more than three dollars for every one dollar spent.

Most recently, we completed a survey of over one thousand people using the Better Health & Medical Network. Over 90 percent of respondents indicated that use of this service increases their ability to understand their medical problems and medical treatments and improves their ability to communicate with their health providers. Over 50 percent indicated that the service improved their and their family's health.

At the same time they also indicated a decrease in unnecessary hospital, emergency room and doctor visits. This should not be surprising since an informed consumer is a basic requirement in a market economy for the efficient delivery of services. By efficient, I mean providing the highest quality services at the lowest cost.

An informed consumer must have the right information at the right time and must be able to apply that information in decision making. Today, we commonly call that person empowered.

Information alone is not enough. We need to support people in using information and using it wisely. Interactive technologies can be an even more important tool in providing this vital component.

An online health community like the Better Health & Medical Network can provide the context and environment that encourages each person to evaluate information with regard to benefits, risks and costs for their own personal circumstances. Online communities can also provide incredibly powerful human support from other people, who, because of their own personal experiences, understand and empathize.

I'd like to share a couple of messages from over five hundred thousand messages we've received in the Better Health & Medical Network.

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1. "I believe I may be the only one in my town that has Primary Sjogrens. There aren't any nearby support groups . . . the Better Health & Medical Forum let's me actively correspond with other folks that have similar problems, like MS or lupus. I can talk to those people and ask questions as to how they handle life's challenges."

2. "I am not only an RN, but also the mother of a child with a genetic disease. He is currently being followed at Johns Hopkins. Although I work in a hospital setting, it's great to have this service at my fingertips! This particular deficiency occurs in about 1 in 100,000 births, so I am eager to find out anything that I can about this syndrome."

3. "You are your husband's greatest resource and his best support. If you want to talk, I check my e-mail almost daily. Many people I have never met have given me courage and hope when all else seemed to be failing me. In the midst of all this, we moved from CA to GA. We lost our entire network of support people and it was difficult. So many thanks go out to the people who share their time online."

4. "I was surprised by the high quality of the information that I downloaded. I found an article released by NIH on a little-known but devastating disease that is effecting the child of a dear friend. We had looked many placed for more information about this rare condition and were unsuccessful. I downloaded the file and plan to send it to my friend. I'm sure he will be delighted with the information, as I am."

But how can you incorporate this technology into what you and the government is doing to empower people toward better health?

First of all, I'd like to applaud the many federal agencies such as the Social Security Administration, the NIH, the AHCPR and the FDA for having already begun to deliver valuable information online. But I think that you and our federal government, especially by leveraging the private sector, can play a even more dramatic and important role in several areas, including:

1. As the largest third-party payer, provide support -- or at least encourage -- greater access to online health services for those covered by federal government programs. Also encourage other governmental and private sector third-party payers to do the same.

Medicare is an excellent example of a governmental program that can dramatically improve the lives of people with this technology while saving money overall. Older people have a high need for health information and support as well as an often unmet need to simply connect.

Evidence shows that they are embracing computer based technology at an even faster rate than younger age groups. In addition, family members would be able to take a more active caring role if supported by online connection with their family members and others.

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Because the infrastructure is already in place in the private sector we do not need to create mammoth projects from scratch. You can take a leadership role with Medicare by focusing efforts on encouraging greater access. These efforts can take many forms including simply promoting use, providing better information for online use and, for those of greatest need, perhaps subsidizing access.

2. Urge all governmental agencies, to put greater emphasis on programs that empower people through improved information and support. For example:

a. Encourage the FDA to focus more on increasing access to information and on helping people use information wisely.

b. Ask the National Library of Medicine and the National Institutes of Health to expand upon the great job they are doing in providing health information and put more emphasis on patients and the general public.

3. Take a leadership role in helping the private sector to provide much better access to less advantaged people, especially those located in rural areas and inner cities. Let's see how we can effectively use community institutions such as health clinics, libraries and churches as centers of access for those that cannot afford to have direct access in their homes.

4. Although, we have built online areas for seven large national voluntary health organizations, additional support is needed to be able to provide this service to the hundreds of smaller voluntary health organizations that serve their tens of millions of members.

5. Through direct communication to your own constituencies and through overall governmental communication programs you could greatly increase the general public's understanding of this important and powerful public health message -- empowerment, through health information and support, improves health & well-being, quality of life and saves money.

In summary, it has already been shown that online technology is an effective tool to empower people to improve their health and quality of life. However, we have a long way to go to reach everyone. Working together we can greatly increase the rate of growth, especially for those that need it the most. We can also help those with special needs get more access.

Although I have made some specific suggestions here today and have more to offer at another time, I turn to you to determine the best ways for our government to deliver on the promise. However, I would like to urge you to move forward quickly and leverage the dynamic changes that are already taking place in the private sector.

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Mr. TOWNS. Thank you very much, Dr. Douma. And I'm certain that we will be calling on you in the days ahead for additional suggestions, comments, and information. So you will get an opportunity to give a lot of time to us, and we welcome it.

Let me—earlier, I indicated that we felt very comfortable because we have this legislative Dream Team. And I talked about Mr. Clinger and I talked about Mr. Shays and I talked about Ms. Collins.

I would like to add to that Dream Team Congresswoman Connie Morella as a part of that legislative Dream Team. And, of course, I would like to add Congressman Barrett. And now, I would like to just yield to him to present the next witness. He's a part of the legislative Dream Team.

Mr. BARRETT. Thank you, Mr. Chairman. I just want to welcome Dr. Gustafson, who is from my alma mater, University of Wisconsin. I spent 7 years there. In those 7 years, I lived in nine different places. You know what student housing is like at Madison. And I'm very much looking forward to hearing your testimony on CHESS, and I welcome your being here today.

Mr. GUSTAFSON. Thank you. I appreciate the opportunity to speak with the Members of Congress. I hope to make three points. The first is that patients can care for themselves. The second point is that technology can help them do that. The third point is that evaluation of these technologies is absolutely essential.

The costs of health care in the United States, as we all know, are among the highest in the world. Why? I think to some extent, at least, it's because so many unnecessary services are being delivered to patients with serious diseases. Let me clarify that. A patient with AIDS can spend weeks in the hospital because his or her opportunistic infection has not been identified early. A person with arthritis can have premature joint replacements if they have not engaged in exercise and diet and proper use of medication.

Patients can help us control costs. Patients can learn to detect opportunistic infections earlier. Patients can adopt proper diet and proper medication and proper exercise. But they need help to do this. They need to want to change their behaviors. They must know how to change their behaviors, and they must have support in order to stick with those behavior changes.

In the past, we were able to count on nurses and social workers, on educators and on doctors to help these people make these changes in their lives. With the advent of DRG's and health maintenance organizations and other forms of managed care, as positive as they are, what that has done has been to limit drastically the amount of those resources that can be brought to bear to help people change their behaviors.

Technology can help fill that gap. CHESS, the Comprehensive Health Enhancement Support System, is a system that has been developed by us at the University of Wisconsin, and it's a system that's aimed at helping patients in crisis deal with major life-threatening crises when they occur. I'm going to talk about one of those crises, and that's breast cancer, although CHESS addresses several of these.

Today, if a woman is diagnosed with breast cancer at the University of Wisconsin or at Harvard Community Health Plan or at

Hartford Hospital or at Group Health Puget Sound or in about 16 different sites around the country, they're given the opportunity to have a computer placed in their home for somewhere around 3 months. And they can use this system in a variety of ways.

And on the chart over there, the one labeled "What is CHESS?" I summarize briefly the 12 CHESS services. But suffice it to say for the purpose of this presentation that there are three categories of CHESS services. One provides information, one provides social support, and one provides help in making and in implementing decisions.

A key part of CHESS is the fact that this information is carefully selected before it goes into the system, and it's carefully coordinated so that people can move between these services very easily.

I think CHESS has probably been the most extensively evaluated consumer health information system. We have had or are engaging in five randomized clinical trials of the system to look at the outcomes that CHESS has had, the effects that CHESS has had on people's lives.

Ilene Kurzman, sitting in the first row is a woman with breast cancer who has been using CHESS for the past few months. She's here in case you would like to ask her any questions about her experience with CHESS.

In addition to the five clinical trials, CHESS has had a number of field tests, one on the South side of Chicago where we placed CHESS in the homes of indigent African-American women and left CHESS there for 8 weeks to see what would happen when they used it; what kind of acceptance, use, and impact. We also have a study funded by the Health Care Financing Administration to place CHESS in the homes of—our target is every woman with breast cancer over the age of 65 in the five-county region surrounding Madison.

So there are a number of tests. I can't go into detail on the results here, but I would like to summarize some of the key findings. My written testimony goes into it in more detail, as do the articles I have provided.

The key findings are these. First, on the average, a person uses CHESS a little more than once a day. In breast cancer, nearly half of those uses occur between 10 at night and 6 in the morning when they can't sleep, when they're worried about things. Across AIDS, breast cancer, and adult children of alcoholics, we have been able to demonstrate a significant improvement in quality of life.

In AIDS, we have been able to demonstrate a reduction in cost of care of about 30 percent. I don't mean to imply that that would happen with breast cancer, other areas. AIDS is one disease where the individual behavior of patients can make a humongous difference in costs of care. In adult children of alcoholics, we have been able to demonstrate that with CHESS, patients are more likely to adhere to other kinds of treatment, specifically group psychotherapy.

And we have been surprised at the costs of operating CHESS. And one of the reasons we have been surprised at it is that because CHESS uses what's considered by industry to be outdated computers, we find that industry is willing to donate those computers to our organizations that are going to be offering CHESS.

We found that it's easy to get refurbished computers that will cost approximately $400. So unlike the $2,000 figure or the $1,000 figure, we're finding the cost of the equipment for CHESS is remarkably small.

But of all of the findings that we have had, probably the most significant one is that the underserved populations are the people that benefit the most from CHESS. They're the ones that have the highest increase in quality of life. They're the ones that most readily seem to accept it. CHESS seems to have a very powerful impact on their life.

I believe that evaluation is absolutely essential for a number of reasons. I'm going to mention three. First, we have many stereotypes about how these systems will be used: Women won't use the system as much as men, minorities won't use them as much as Caucasians, less educated won't use them as much as more educated. From what we have been able to tell, each of these stereotypes is wrong, and there are many more stereotypes out there that need to be evaluated.

But the second and maybe even more important reason for careful evaluation. There is a proliferation of these systems that's occurring now. And women and men who are in crisis, can't be expected to operate under "Buyer beware." They need to have help in intelligently choosing among the systems that are available to them.

We have to worry about the quality of these systems. We have to worry more about the impact on their lives as opposed to just the number of uses of a system. I would like to ask Congress to do one specific thing, although Allen has pointed out many others. I would just like to concentrate on this one for the time being.

I hope that Congress will increase the amount of resources that are available for carrying out evaluations of these systems. The Agency for Health Care Policy and Research, HCFA, and NIH have all begun to move in these areas. And providing them with the resources to make careful assessments of these systems, I think, will make a big difference.

I've tried to make three points. The first point is that patients can care for themselves. The second is that technology can help them do that. And the third is that Federal support for evaluation of that technology on an outcomes basis is absolutely essential.

Thank you for your time.

[The prepared statement of Mr. Gustafson follows:]

Statement of David H. Gustafson, Ph.D.
Subcommittee on Human Resources and Intergovernmental Relations

July 26, 1996

Good morning Mr. Chairman and Members of the Subcommittee. I first got into computer based crisis support systems in 1973 with a grant from the National Institutes of Mental Health with which we developed a system to predict whether patients complaining of suicidal thoughts would make an attempt on their lives. We found that patient actually preferred talking to a computer rather than to a provider. Ten years later with funding from the Kellogg Foundation we developed a system (called BARN) to help teenagers deal with issues such as smoking, sex, alcohol and other drugs. While the system was not much good at preventing onset of these risk taking behaviors it was very good at helping kids in trouble change their behaviors. We concluded that computers could be very powerful in helping people deal with crises. The Kellogg Foundation then awarded us another grant to develop CHESS, the Comprehensive Health Enhancement Support System. I am very pleased to have this opportunity to present this discussion of consumer health informatics and to describe CHESS.

The development of computer technology has brought with it enormous potential, outlandish promises and ever increasing progress. In the last few years the increased power and reduced cost of personal computers as well as the advent of Internet has allowed some of that potential to be realized. In health care we have seen much investment in computer systems for health care providers. But until recently patients have not benefited directly from computer systems that help them cope with their injuries and illnesses. In the 1990s that began to change. Over the past five years our team of decision, information, education, communication and medical scientists affiliated with the University of Wisconsin Center for Health Systems Research and Analysis have been developing CHESS to help people in crisis overcome the barriers mentioned above (Gustafson, et al., 1987; Bosworth & Gustafson, 1991; Gustafson, et al., 1992). Funding for that development came first from the W.K. Kellogg Foundation and later from Robert Wood Johnson and Alzheimer's Foundations.

Description of CHESS

CHESS is an education and risk management technology for improving patient quality of life, promoting adherence to treatment and reducing costs of care. Using a CHESS personal computer typically placed at home, patients and family members read brief answers to many questions, detailed articles and descriptions of services they may need. They anonymously ask questions of experts, communicate with and read personal accounts of others with similar problems. CHESS problem solving tools help patients monitor their health status, make important health decisions and plan how to implement those decisions. Brief descriptions of each service follow:

CHESS Information Services:

Questions & Answers is a data base of short answers to commonly asked questions about the particular health crisis. The questions were derived from surveys, focus groups and in-depth interviews with users and providers. They are answered by teams of experts. Like all other information services, users can access the material through keywords or through a hierarchical menu of chapters and sections. .

Instant Library contains full text articles to provide more depth and differing perspectives of issues within the topics. Material includes brochures and pamphlets, as well as scientific articles. We reproduce materials in the public domain (such as the National Cancer Institute), as well as material for which we have sought and obtained copyright permission..

Getting Help is a tutorial which helps users become knowledgeable consumers for approximately 200 services (e.g. mammograms, 12-step programs, therapists, etc.). For each service, the tutorial provides a description, how to identify and choose a provider, and how to get the most benefits.

Referral Directory is a data base of national public and non-profit agencies that offer information, support and referrals. The data base is accessible via keywords or a hierarchical menu of chapters and sections. An option to create a local referral directory is available.

Personal Stories are real-life accounts of people who have struggled with breast cancer. Stories are written from interviews by professional journalists. Identity is hidden by removing distinctive personal information. Specific information in the 3-5 page general stories can be expanded for more detail by pressing a key.

Dictionary defines medical and technical terms in common English to enhance users' understanding. Dictionaries currently operate in the Breast Cancer and AIDS/HIV volumes.

CHESS Social Support Services:

Discussion Groups allows users to use electronic bulletin boards to communicate with a professionally facilitated small group (<45) . Using a code name users share anonymous support and information. To ensure privacy, CHESS discussion groups are open only to authorized CHESS users. Others are open to all CHESS users. Users can bookmark, for easy retrieval, messages they would like to see again. In this evaluation, all discussions (whether on stand-alone CHESS or on Internet treatments) will be facilitated to promote supportive interactions and limit incorrect information about breast cancer. Since groups cannot be monitored 24 hours a day, we place disclaimers on discussion groups.

Ask an Expert allows users to write a question and receive a *personal answer* from a breast cancer expert. By referring to the user's health and treatment *Profile* (see below), the expert can offer a personalized response. By selecting appropriate keywords, the expert can can link the user to other information in CHESS. Since many questions areof general interest, the expert can edit and place a depersonalized response in *Open Expert* for for all CHESS users.

CHESS Problem-Solving Services:

Decision Aid uses utility theory to help people think through difficult decisions: identifying and learning about options, selecting and weighting decision criteria, and applying criteria to options. Decision Aid offers a generic version of the program which users can apply to any decision, and tailored decision aids providing more specific details developed by panels of experts. In breast cancer for instance, tailored decisions address: breast surgery, chemotherapy, oopherectomy, clinical trials, tamoxifen and bone marrow transplant.

Action Plan helps users implement a decision they have made. It is one thing (for instance) to decide to adopt a low fat diet and another to stay with it. Action Plan uses statistical decision and behavior change theories to help users identify goals, resources and social supports as well as obstacles and how they will overcome them. The generic Action Plan can be used to plan any behavior change. Tailored Action Plans provide more details for adopting particularly important changes.

CHESS Self-Monitoring and Guidance Services:

Profile allows users to record their physical and emotional health; treatment history and plans; and demographic information.. Experts answering Ask an Expert questions can consult users' *Profiles* to answer questions more precisely. Users are complete their Profile at installation and update it monthly.

Health Charts helps users: (1) track changes in their health and well-being over time, (2) share their charts with other users if they so choose, (3) identify key concerns, which can (4) link them to relevant CHESS material. Every two weeks users are encouraged to complete the health chart as well as list, circumstances or actions that might affect their health or well-being.

The Status of CHESS

CHESS currently has fully functioning modules for AIDS and breast cancer. Its modules on acquaintance rape, adult children of alcoholics, stress and academic failure need modest changes to move them from a research environment to full operation. New modules are being developed for: parents and partners of alcoholics, heart attack victims and Alzheimer's care givers.

AIDS is a fully functioning module that has been subjected to two clinical trials and several field tests involving nearly 600 HIV infected people. It is operating in Madison, Milwaukee, Seattle, Minneapolis, and the San Francisco bay area. We extensively update our modules once a year. The AIDS module has recently completed an update.

Breast Cancer is also a fully functioning module. It is operating in Minneapolis, Madison, Boston, Chicago, London Ontario, Hartford Connecticut and Yakima Washington, with new sites soon to implement it in Seattle, Milwaukee, and Burlington

Vermont. The breast cancer module was recently updated. It is being tested in two clinical trials and several field tests involving over 400 women with breast cancer.

Adult Children of Alcoholics, Acquaintance Rape and Stress Management modules have all been field tested but minor changes are needed before they are ready for full scale demonstration.

Academic Failure, Parents and Partners of Alcoholics, Alzheimer's Care Givers and Heart Attack modules are scheduled for completion by the end of the year.

The copyright for CHESS has been assigned to the Wisconsin Alumni Research Foundation which is the patent and licensing organization for the University of Wisconsin.

In order to continue to develop new CHESS modules and to identify the most cost effective means for disseminating CHESS, a research consortium has been formed. It size is limited to ten organizations and is currently composed of the University of Wisconsin, Fletcher Allen Health System in Vermont, Group Health Cooperative Puget Sound, Hartford Hospital in Connecticut, Harvard Pilgrim Health Plan, HealthPartners HMO in Minnesota, Oschner / Sisters of Charity Health Plan in Louisiana.

The Credibility and Measured Benefits of CHESS

CHESS has gained the attention of leading academic and government organizations that see it as a model. Mass-media has featured CHESS on more than 20 television programs and news reports. This reputation comes in part because CHESS has (to the best of our knowledge) been studied more extensively that any other consumer health information product regardless of presentation format. Field tests and randomized clinical trials have been funded initially by the Agency for Health Care Policy and Research, and later through funding from NIH, HCFA and our CHESS Health Education Consortium. The following is a brief summary of what has been learned.

CHESS content is based on a thorough assessment of customer needs. We believe that a thorough understanding of customer needs is absolutely essential to developing CHESS modules. Our needs assessment process has been the subject of several articles and is one of the most frequent inquiries made to our Center for Health Systems Research and Analysis. We first interview both patients and families using a critical incident approach to discover their needs rather than assume we know them. Then we send out a survey to several hundred patients and families to set priorities on those needs and to rate satisfaction with service provided. For instance in breast cancer a survey of about 150 items was completed by over 400 patients and families. The needs assessment is important for three reasons. First every item (even the least important) on the survey is the focus of some element of the CHESS modules. Second, statistical analysis of the data helps us cluster the needs into the theme areas around which CHESS is organized. Third, the more important the needs, the more attention they receive in CHESS.

CHESS is used and valued by a wide variety of people, including the underserved. The CHESS interface is designed to be extremely easy to use. In studies with breast cancer and AIDS patients as well as adult children of alcoholics nearly 80% of all patients offered CHESS accept it. Our groups of thirty patients typically use CHESS 1800 times per month. Between 33% and 48% of uses occur between 10:00 PM and 8:00 AM[1]. Minority, socio-economic & age status don't affect use. Indigent African-American patients[2] and people with low education[3] use CHESS as much as other groups but in different ways (using information and expert systems services more and communication less). CHESS created positive emotions (e.g. hope)[4]; 80% of users preferred CHESS to support groups & counselors[5]. We currently are installing CHESS in the homes of women with breast cancer all of whom are over age 65 through a contract with Medicare intended to examine the practicality of a population-wide implementation of CHESS. As a result of this test, about 50% of all Medicare eligible women in a five county area surrounding Madison WI who have been diagnosed with breast cancer since March have used CHESS.

CHESS improves quality of life, lowers costs of care, unburdens providers. In a 3-year clinical trial of 200 HIV-infected people, half of whom received CHESS[6]: Quality of life significantly improved in the people having access to CHESS. Time spent with clinicians dropped 15% in the CHESS group compared to controls. Cost of care appeared to decrease by $400 per person per month (30% of total cost). It may be that CHESS helps patients identify opportunistic infections earlier and thus allow them to be treated more quickly and less expensively. A clinical trial in breast cancer (funded by NIH) has just completed its first phase. Early results of the evaluation found that CHESS improved quality of life compared to the control group with the effect being particularly strong in women undergoing chemotherapy. There also may be a reduction in the number of visits to physician offices.

CHESS may enhance treatments In a small pilot study, 24 adult children of alcoholics received either CHESS, professional psychotherapy counseling, or CHESS plus counseling. Attendance at psychotherapy sessions improved from 38% to 80% when people also had CHESS. CHESS + psychotherapy patients used CHESS 30% more than people who had CHESS-alone. Quality of life improved on all six dimensions with CHESS, and on five dimensions with CHESS-plus-psychotherapy. Quality of life deteriorated on four dimensions with psychotherapy-only. While this is a small test it does suggest that CHESS may improve adherence to therapy at the same time that it improves quality of life.

User Comments Quantitative findings are very important but the evaluation results are often better understood from comments made by users.

Nearly every day unsolicited testimonials arrive either as comments in the Discussion Group or as part of letters to experts or in correspondence sent directly to the developers. Here is a small sampling of those comments.

- "Thank you for CHESS. Without it, I don't think I would have made it through this time in my life."

- "Before CHESS I wanted to kill myself. Thank God, CHESS saved my life. When I'm depressed all I do is get on the computer . There are so many out there who need CHESS like I did.
- "I am inspired by all of your courage, spirit, and willingness to "be there" for each other. It is with a small grin that I turn on the ole machine and look for your thoughts."
- "CHESS is a big help to me; a wonderful source of information and support. I lost my husband two years ago. When I found out I had breast cancer I had no one to tell. When CHESS came along it was a Godsend."
- "I thank God every day for the CHESS system. We are very fortunate to be part of this group."
- "There is so much information on this system. One night when I couldn't sleep I spent two hours reading about the research using adjunctive chemotherapy when the nodes are negative."
- "Having all the information has allowed me to feel confident and peaceful with my diagnosis."
- "I have gotten as far as I have because of the CHESS program. I have grown by leaps and bounds, as if a whole new person has come out from inside me."
- "I will miss you when you leave CHESS but will carry you in my heart forever."

CHESS and Internet-based systems.

I would like to make a few comments about the Internet. Like the computer field in its early days, Internet brings enormous potential, outlandish promises and ever increasing progress. In concept, the Internet offers important advantages over stand-alone personal computers. Programs can be updated easily and quickly. Users are able to talk with hundreds of people facing problems similar to theirs. Vast amounts of material can be accessed on the Internet. Low cost hardware (Network Computers) will be able to run programs on Internet and many different computer platforms (including PC and Macintosh) are able to access the Internet. Enormous investments are being made in the Internet so in time it will be able to support complex programs like those in CHESS although it cannot support them now. Finally the Internet reaches many people with Web sites reporting thousands of "hits" per day.

But is the Internet really a viable way to help people in crisis? Many are old and have never used a computer before. They see themselves in a life and death situation they have never faced before. They have embarrassing questions to ask and need to "speak" in confidence. They desperately want help they can trust.

Internet requires continuous use of a phone line. We found that people in crisis do not want to tie up their phone line and prevent friends and family from calling. This is why CHESS uses a phone line only a few minutes a day, to down and up-load messages.

CHESS discussion groups are limited to 45 carefully screened people so they can get to know and trust each other. The discussion groups on the Internet often serve thousands of users including researchers and browsers.

Internet can be difficult to use. It requires a mouse and can freeze or operate slowly. Many people facing crises (e.g. older patients) cannot tolerate the eye-hand coordination needed to use a mouse.

CHESS material is chosen to address specific needs identified from studies of patients and is coordinated so a person can quickly find material they want at the level of depth they want it. The masses of largely uncoordinated material of varying quality on the Internet means users can spend hours never finding what they need.

Network Computers will available for about, half the cost of the least expensive PC. CHESS operates on computers considered outdated by many corporations. Providers have found employers willing to donate such computers for CHESS use. Others purchase refurbished computers for $400 or less. Internet may not be less expensive.

There have been virtually no outcome evaluations of Internet programs in general and particularly for people in crisis. Developers report number of visits (hits) to a Web site. Are people really getting anything out of those hits? Does it make a difference in their lives?

Please do not misinterpret my comments. I believe that in time the Internet will be an important way (possibly the best way) to deliver computer based support to people in crisis. In fact, CHESS is being designed to operate on the Internet when it is able to support the services CHESS offers. But I also believe current Internet capabilities have been oversold. Its impact on quality of life and cost of care needs to be carefully evaluated and it progress monitored.

The future of Crisis Support Systems

If the Internet is not in the immediate future for systems such as CHESS, what is? I believe there are several things that need to be done:

- Increase the number of health crises that are covered by systems like CHESS. Diabetes, asthma, spinal chord injury, depression, end stage renal disease are a just a few of the health areas for which patients could play a significant role if properly prepared. patient

- Reduce the cost of developing new modules for systems like CHESS. Like any technologies in their infancy most of our current energies are put into developing an infrastructure that meets patient and family needs. But development of these systems can be costly. We all need to become much more efficient in those development processes.

- Become more efficient in delivering systems like CHESS. Just as we need to be more efficient in developing new crisis support systems, we need to be more efficient in delivering those systems to people in need. The underserved benefit so much from systems like CHESS. But at the same time we need to make it as practical as possible to provide them with these systems.

- Take advantage of new technological advances. As computer technology moves ahead we need to stay just enough behind the times to take advantage of low cost equipment and yet build on the most important technology advances. In the next few years some computers with CD ROM will be considered outdated and thus available

at low cost. Systems like CHESS then need to take advantage of sound, video and animation to communicate key issues.

- Increase awareness of crisis support systems. As these systems are proven to be effective we need to reduce barriers to their acceptance by providers and patients. To some extent our Health Education Consortium is doing this for CHESS by expanding the number of settings using it. But we must find ways of sharing our experiences with the whole health field.

- Integrate crisis support systems with provider organizations. At this point systems like CHESS operate independently of health care providers. There is no link between the material in CHESS and the medical record. Hence patients cannot see laboratory test results and the doctor cannot follow the patient's progress as it is documented in CHESS. The potential for crisis support systems to reduce cost of care will be fully realized only when this integration takes place.

The need for evaluation

The proliferation of computer systems is just beginning. At this point few of them directly address the needs of people in crisis. However, the number of stand alone and Internet-based systems for people in crisis will greatly expand. And the time of crisis is not a time when we simply say "buyer beware". We know that bad decisions are most likely to occur in times of crisis. I am a systems developer and a researcher. But I am also a partner of a woman with breast cancer. I experienced the pain and frustration of seeking information and support. Computer systems such as CHESS can help a lot of people. But people in crisis need to have guidance on how to choose high quality systems. They need to know what works and what doesn't.

As a researcher I also know how surprised we have been from the results of our evaluations of CHESS. We all have our stereotypes: Older people won't use computers. Minorities won't use computers. Women won't use computers. The less educated can't use computers. These systems will only broaden the gap between the information rich and information poor. But the findings from our research are that none of these stereotypes are true. And we would not have known that without research.

There are so many unanswered questions, not the least of which is just how effective are Internet based systems compared to stand-alone systems like CHESS. There are many others: How effective are computer based support systems compared to psychotherapy? What is the most cost effective way to get computer support to underserved people? How thorough must language translation be to help Spanish speaking (and other) people benefit from CHESS-like systems? We have our stereotypes. But we don't know and we need to know.

It is for these reasons that I ask you to expand the funding for research and development of computer based crisis support systems and for communicating the results of this research to people who need to know. We spend less than 1% of our federal research dollars on evaluation. The level of funding for research of this type is very small and seems to be getting smaller. But it is through this kind of research that we can quickly translate the results of basic research to the public. We need your

help, Mr. Chairman and Members of the Committee, to ensure that the promise of technology is met, that the real capabilities of these systems are understood and that developments of future systems are based on the firm foundation of fact not stereotypes.

Mr. Chairman, that concludes my testimony. I would be happy to answer any questions you may have.

David H. Gustafson, Ph.D.
Biographical Sketch

David Gustafson is a Professor of Industrial Engineering and Preventive Medicine and the Founder of the Center for Health Systems Research and Analysis at the University of Wisconsin-Madison. Using decision and systems analysis, Dr. Gustafson develops and evaluates computer systems to help people in crisis. His research group has created computer systems to help teenagers reduce problems such as alcohol and other drug abuse, sexual activity and smoking and to help adults deal with crises such as suicide, breast cancer, AIDS and alcohol abuse. In addition to developing these systems Dr. Gustafson has conducted extensive research to understand how groups such as the elderly, minorities and women respond to and are affected by such computer based health support systems. Dr. Gustafson led the evaluation and redesign of Wisconsin's long term care regulatory process and conducted numerous studies aimed at understanding and developing systems to meet the needs of elderly residents in long term care facilities. His work has received the American Medical Association Award for Excellence in Prevention and Education and the University of Wisconsin's Onstad Service to Society Award. He will be testifying about CHESS, the Comprehensive Health Enhancement Support System, and the research that has emanated from it.

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Mr. TOWNS. Thank you very much. And let me say before we start with the next witness, there's a vote on, and that means that we have to go over to the floor and cast our vote. We were trying to wait for the chairman to return. But we will just take a quick recess here. I'm certain that he should return in just a few moments.

So Connie, I don't know—I guess we should just break here, right?

Dr. SHELLEY. I think waiting would make the most sense. Why don't you go ahead?

Mr. TOWNS. OK. We'll be right back.

[Recess.]

Mr. SHAYS. I call this hearing back to order. And I understand two witnesses we have heard from, correct?

Dr. SHELLEY. Yes; you have.

Mr. SHAYS. Who's next in line?

Dr. SHELLEY. I think I am, sir.

Mr. SHAYS. Thank you, Dr. Shelley.

Dr. SHELLEY. First, I also would like to thank the committee, the GAO, and you particularly, Congressman Shays, for this invitation to come and speak. I view myself as being more of a voice of caution, interestingly enough. I'm a lover of this technology and have been a long supporter of computerization, but this is a bit of a voice from the front lines I would like to give you.

We live in a time of great change. And among the most dramatic sources of flux are the great revolutions now occurring in our health care system and the rapid introduction of information technology. It was inevitable that these two great social revolutions would meet and overlap, and consumer medical informatics is the latest——

Mr. SHAYS. Dr. Shelley, if you would move that mic a little to your——

Dr. SHELLEY. You've got it. Do you have me now?

Mr. SHAYS. And then lower it down just a little bit, since your voice is down.

Dr. SHELLEY. There we go. Is that a little better?

Mr. SHAYS. Yes.

Dr. SHELLEY. OK. Good. Thank you.

Well, consumer medical informatics is the evidence of the overlap of these two great revolutions, managed health care and computer technology, coming together. In the 1960's, computers were used to track the administrative aspects of medical care. In the 1970's, we had laboratory computers tracking medical results. In the 1980's, hospital-wide systems were introduced to help the clinician in the care of his patients.

Now in the 1990's, patients are beginning to directly interact with these computer systems. Now, this is occurring for a number of reasons, which a lot of people have already alluded to, but in particular, a reduction in the cost of computer technology and a perception that patient entered information will somehow be more accurate and more cost effective. And also, our patients are becoming more sophisticated, and their expectations are increasing for the use of this particular type of technology.

I believe it behooves the Government to understand this technology, because they are the largest consumers of medical services. And before they begin to hire a lot of robo-docs, they had better understand what the advantages and the pitfalls are.

First, let me tell you, I'm a practicing anesthesiologist from a large academic medical center where I have the privilege of often working with the newest medical technology. This experience has included the attempt to introduce the Health Quiz device to my medical center and to the Lebanon VA Medical Center. And this testimony basically is based on that experience.

I've used this device now with over 1,000 patients in over 2 years. And I call my testimony primarily the rise and fall and possible resurrection of the Health Quiz device, a case study in vision versus reality. Essentially what this device was designed to do was to make up for some of the changes we presently have occurring in the medical system.

Some 10, 15 years ago, if you came into the hospital for an operation, the anesthesiologist would come by the night before, sit by your bedside and have a conversation with you about what your anesthesia was going to be like. Well, we live now in the days of sort of MacDonald's drive-up medicine, where one arrives on the morning of surgery and gets quickly ushered into an operating room. And this technology is an attempt to extract information from a patient in a more successful manner.

This device, which was a vision of Dr. Michael Roizen, who is a chairman of anesthesia at Chicago University and a leading expert in this field, was brilliant. He simply wanted a simple box that had "yes," "no," "not sure" buttons on it and then a button that simply said "next question." The patient was asked approximately 100 questions with this box, and then a very nice report with analysis was produced.

There were a number of studies done on this device by Dr. Roizen through the late 1980's and early 1990's. It looked like it was going to be a winner. There was a good correlation between the answers a patient put into the box and what came out if you later questioned. Also, there seemed to be some early indications that there would be cost savings through reduced testing.

In the summer of 1994, the device was successfully demonstrated at Hershey Medical Center, where I am, and I was quite impressed with the quality and usability of it. I even convinced the company to give me 14 devices on a test basis through a luminary account.

And I, with great enthusiasm and fanfare, entered this project. Although problems early on began to crop up, from the first day, who, exactly was going to put these devices out into the surgical clinics, and who, exactly, was going to maintain these devices out there.

I pointed out these large cost savings that were going to be incurred by my medical center, and they immediately asked me, "And exactly whose budget line, exactly would these cost savings come off of?" so they could hire me personnel. Should they take money away from the laboratory because I was ordering less labs, should they cut my salary? Because obviously, I'm doing less work, I'm using now a computer system.

The most telling blow I can tell you, though, came from my fellow anesthesiologists. Much to my surprise, the acceptance of the Health Quiz was not automatic. Some complained that the reports were not detailed enough. Others quibbled about the recommendations.

And in addition, there seemed to be this unspoken fear about being replaced by a box. It's important to understand that physicians now feel increasing loss of autonomy in their practices. And here it is, I'm introducing a box that's quizzing the patient and having a conversation about their upcoming medical care. As opposed to being a helper, they viewed this as being another barrier between them and the patient.

By the way, I discovered that my experience was by no means isolated. One of our large local community centers bought a number of these boxes, introduced them, and then quietly withdrew them. Some of the weaknesses that we found with the system, the biggest one was questionable acceptance by the physicians. There were hardware and software problems. The batteries would often go dead. There was one stage we had to do a massive recall because there was a shortage that occurred in the software system. There were problems.

There was also a lack of flexibility in judgment and a lack of standardization of the information that was collected. It's important to note that not all of my experiences were negative, though. At the Lebanon VA, my vets actually liked this box a great deal. They called it the "Nintendo anesthesiologist" and seemed to appreciate it. And my anesthesiologists out there seemed to be a little bit more openminded.

The strengths we found included consistency and legibility. There were reported cost savings. And from some medical legal considerations, I could prove what a patient was asked at a specific time and a specific place.

This device at its peak was installed in 250 hospitals. It has now, though, been withdrawn by the company from the marketplace. Now, interestingly, the Health Quiz story doesn't end here. Dr. Roizen is committed to this vision, and he's now working to introduce this same system via the World Wide Web. And this may resurrect itself where one, at home, would go ahead and answer the quiz through your own computers. I wish him well on this.

My final recommendations to the committee. Believe it or not, I'm not coming looking for money or funds. I think the Government has a tremendous advantage here, in that even though it's often compelled to act in certain arenas, such as national security, in this particular case, we have powerful market forces already in play. And nobody can particularly predict what the final outcome of these are going to be.

I would recommend that the Government take a "wait-and-see" posture. In particular, what I would recommend is to allow the academic centers to continue to develop these systems and then allow the private sector to shake out the winners and losers. I would recommend avoiding mandating any specific solutions early on and wait for standardization of equipment and data. And that concludes it. I'm open for any question. And I thank you once again for an opportunity like this.

[The prepared statement of Dr. Shelley follows:]

Testimony of
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Before the
House Committee on Government Reform and Oversight,
Subcommittee on Human Resources and Intergovernmental Relations
July 26, 1996

Introduction
We live in a time of great change. Among the most dramatic sources of flux are the ongoing changes in our healthcare system and the rapid introduction of information technology. It was inevitable that these two great social revolutions would meet and overlap. Consumer medical informatics is the latest evidence of this interaction.

Background
Since the 1960's, computer's have been used to track the administrative aspects of medical care. Starting in the 1970's, task specific computer systems appeared in clinical laboratories. In the 1980's, hospital wide systems were introduced to aid the clinician in the care of his patients. Now in the 1990's, patient's are starting to interact directly with this technology. This is occurring for a number of reasons:

1. Reduced cost of computer technology.
2. The perception that patient entered information through direct interaction with computers will be a) more accurate and b) more cost effective.
3. Increased patient sophistication and expectation.

As the largest consumer of health care services it behooves the government to remain abreast of advances in this area and the potential pitfalls of these "Robo-docs".

As a practicing anesthesiologist (M.D.,Ph.D. (Biochem): Anesthesia & Internal Medicine) at a large academic medical center I have the privilege of often working with the latest medical technology. This experience has included the attempt to introduce the HealthQuiz® device to the Hershey Medical Center and the Lebanon VA Medical Center. This testimony is based on that experience. I have no affiliation with the company (Nellcor, CA) that produced the device & I have no intent of entering this field myself. All the opinions, I express here are my own and in no way represents an official statement by my employer, Penn State University. They are, however, based on two years experience and over a thousand patient encounters with the device. During that time I actively sought the opinions of, and reactions to, the device from both patients and medical staff.

The Rise and Fall (and Resurrection?) of the HealthQuiz®
A case study in vision vs. reality

Background
As anyone who has undergone surgery can tell you, a significant number of people are involved. Among those involved is the anesthesiologist. In the past, a vast majority of patients were admitted the night before surgery and met their anesthesiologist at their bedside. Now in the 1990's, cost saving considerations require that the patient be admitted the same day as their surgery. This has greatly reduced the amount of time that can be dedicated to the pre-operative evaluation. In response this, health care providers have implemented a number of solutions including pre-op clinics and automated screening systems.

The Vision
One such solution was developed by Dr. Michael Roizen. Dr. Roizen is the chairman of anesthesia at the University of Chicago and a recognized expert in the field of pre-operative evaluation of patients. Dr. Roizen envisioned a simple device that could be given to patients, and would ask a series of health related questions. The device is a paragon of user-friendly design with only four buttons for the patient to interact with "Yes, No, Not Sure & Next Question". The questions are simple and straight forward. The answers to these questions could then be analyzed and used to create a report that would summarize the findings and make recommendations based on tested clinical algorithms.

The Rise
The initial research studies and response of the anesthesia community appeared to be quite positive. A number of studies were done that seemed to indicate good patient acceptance and the potential of significant cost savings from the reduction in laboratory testing. This device known as the HealthQuiz was demonstrated at countless anesthesia conferences. (See attachments for marketing literature and sample reports generated by the HealthQuiz device.) Marketed by Nellcor (Pleasanton, CA), a successful medical equipment manufacturer, the success of this product seemed to be assured.

In the summer of 1994, the device was successfully demonstrated in the Hershey Medical Center Pre-Admission Center (where I am the medical director). I was quite impressed with the quality and usability of the generated reports. After explaining the potential I saw in this device Nellcor agreed to make Hershey Medical Center an "Luminary Account" with access to 14 cost-free HealthQuiz devices and associated support equipment. I have also attached to this testimony the letter I sent out to the Surgical Clinic Directors in January, 1995 informing them of my plans for the device. The advantages as I saw them then included:

1. Reduced cost of pre-operative testing.
2. Increased patient convenience.
3. The opportunity for clinical research
4. Overall improved patient care.

Reality

It was with great fanfare and enthusiasm I entered this project. Early on though, problems began to crop up. From the first day, the question came up as to who exactly was going to place and maintain these devices. My overall plan called for these devices to be placed in the surgical clinics and operated by clinic personnel. The hospital administration while expressing great support for the project lacked the resources to give personnel for this project. While cost savings were projected it was not clear how these "extra" funds would be tracked and redistributed.

It soon became apparent I, myself was going to have to place and maintain the devices. Next issue was who was going to give the devices to the patients and printout the reports. In a number of clinics (including mine!), the nurses and receptionists reported being too busy to have additional tasks be given to them. It was quite apparent that the clinic personnel did not feel any invested interest in using a device which did not directly impact on their responsibilities.

The Fall

The final and most telling blow came from my fellow anesthesiologists. Much to my surprise, acceptance of the HealthQuiz was not automatic. Some complained that the reports were not detailed enough, others disagreed with the recommendations regarding pre-operative testing. In addition, there appeared to be an unspoken fear about being "replaced by a box". Whatever the reason, I soon found myself as the lone voice of support for the HealthQuiz.

I also discovered that my experience was by no means isolated. One of our large local community hospitals had purchased a number of HealthQuiz devices but after a couple of months had returned them to the manufacture. They reported that the device had actually *increased* the amount of testing being done. For example, if a patient reported chest pain of any cause (i.e. broken ribs) the device would order an EKG. In addition, hardware problems seem to plague the device requiring frequent replacement. In summary, the weaknesses I found included:

1. Questionable acceptance by physicians.
2. Hardware & software problems.
3. Lack of flexibility & judgment.
4. Lack of standardization.

It is important to note that not all my experiences with the HealthQuiz were negative. At our local VA medical center (Lebanon, PA) the device had better acceptance. The list of

questions asked of the patients appeared to be well focused on both cardiopulmonary and substance abuse problems (unfortunately both common among our veterans). In addition, the acceptance by our veterans of the device was excellent. In summary, the strengths I found included:

Strengths
1. Consistency
2. Legibility
3. Reported cost savings
4. Medical-legal considerations

It came as no great surprise when three months ago, after a merger with Puritan Bennett, Nellcor decided to withdraw the device from the market place. Speaking recently with Dr. Roizen, he reported to me that at it's peak the device had been installed in 250 hospitals and is still being used at approximately 50 locations.

Resurrection
Interestingly, the HealthQuiz story does not end there. Dr. Roizen has redesigned the software so that it now works through the World Wide Web. It is his hope that patients will complete the questionnaire in the privacy of their home, long before their scheduled surgery. I, for one, will be following it's progress closely.

My final recommendations to the Committee

The government is often compelled to act because of it's special role in our lives. In the case of medical informatics, powerful market forces are already in place and operating. At this stage, both the medical and the computer fields are undergoing tremendous transformations. No one can predict even the short term outcome of the evolutionary forces in place. I would recommend that the government take a "wait and see" posture. Specifically:

1. Supporting research into these efforts, focused in the academic centers.
2. Allowing the private sector to sort out the cost effective solutions.
3. Avoiding mandating any specific solutions.
4. Wait for standardization of equipment and data.

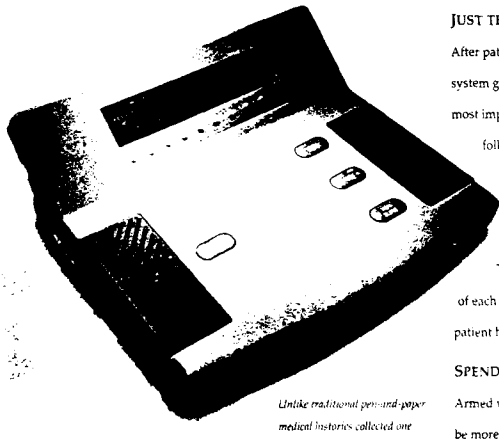
HEALTHQUIZ

A patient-driven medical history of preventive care systems.

*More patients. **Less time. And a lot more paperwork.** It's a way of life in medicine today. And although a thorough patient history is one of the most important pieces of information you can have about your patients, it's also one of the most time-consuming to collect.*

INTRODUCING HEALTHQUIZ.

HEALTHQUIZ is a patient-driven medical history system developed by practicing physicians. Using a simple, battery-powered device, your patients can complete their own medical history in about fifteen minutes. With the touch of a button, patients answer a series of yes or no questions. There's no keyboard, no mouse – nothing to confuse or intimidate your patients.



Unlike traditional pen-and-paper medical histories collected one at a time by the clinician, the HEALTHQUIZ system allows patients to complete their own history by responding to a series of yes or no questions. HEALTHQUIZ represents a significant advancement in the efficiency, quality and cost-effectiveness of gathering patient information.

JUST THE FACTS.

After patients have completed their history, the *HEALTHQUIZ* system generates a one-page report for you that summarizes the most important information, flags issues requiring more detailed follow-up, and even suggests patient-specific tests or other interventions. Each *HEALTHQUIZ* application asks questions and makes suggestions based on established guidelines and practice standards.

The *HEALTHQUIZ* system creates an electronic record of each patient's medical history and lets you store up to 200 patient histories on a small data card.

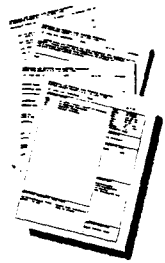
SPEND YOUR TIME DOING WHAT YOU DO BEST.

Armed with the results of a thorough, consistent history, you can be more productive during the time you spend with each patient because you already know where to focus your attention. The *HEALTHQUIZ* system allows you to spend time doing what you do best – *caring for your patients.*

NELLCOR®

HEALTHQUIZ

The historian of the future.



HEALTHQUIZ offers you a choice of summary reports.

HEALTHQUIZ has a brightly lit screen where patients are presented with a series of easy-to-understand yes or no questions. Decision trees are used to select appropriate questions for each patient to answer. This allows for follow-up questions while keeping the overall questionnaire short.

IT'S SIMPLE.

The *HEALTHQUIZ* system is easy to use and simple to learn – for you and your patients. Just enter a few basic facts about the patient, such as age, sex and weight, then hand the *HEALTHQUIZ* device to your patient. All the instructions a patient needs are right there on the screen. The questions are written in language easily understood by a broad range of patients.

- Frees clinician time by having patients enter their own health history
- Collects a standardized, thorough medical history from each patient
- Provides a printed one-page report summarizing the patient's medical history
- Suggests patient-specific tests or other interventions based upon established practice standards
- Creates an electronic record of each patient history
- Allows patients more privacy when answering sensitive or personal questions

HEALTHQUIZ DEVICE

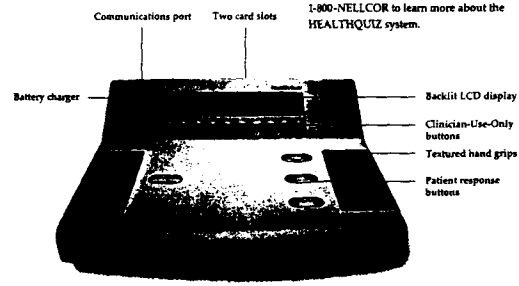
Weight:	2 kg
Dimensions:	267 x 230 x 92 mm
Power:	110 V battery charger
Battery:	12 V rechargeable nickel metal hydride
Battery Life:	8 hours typical*
Display:	Backlit LCD
Standards:	UL 1950; IEC-950; CSA 22.2 950; FCC Class B; VDE 0871 Class B
Modem:	Internal; Hayes compatible, 1200 bps
Serial Data Port:	RS-232 protocol

APPLICATION PROGRAM CARDS AND DATA STORAGE CARDS

Dimensions:	54 x 86 x 3.3 mm
Standard:	68-pin PCMCIA memory card; type I
Memory:	Static RAM; 512 KB
Storage Capacity:	200 patient records (per card)
Patient Record File:	Comma-delimited ASCII text files

*Typical usage assumes backlight on 70% of the time. Specifications are subject to change without notice.

Call your Nellcor representative or 1-800-NELLCOR to learn more about the HEALTHQUIZ system.



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47 y/o WF taking NSAID's, hx GI bleeding, hx smoking

Nellcor Incorporated **HEALTHQUIZ PRESCREEN**
PATIENT SUMMARY REPORT v.2.0 (c) 1992, 1993

47 year old CAUCASIAN FEMALE ID # 10002

SYMPTOMS REVIEW

METAB	Arthritis
HEME/ONC	?? Hx Clotting Problem
PULM	Hx Pneumonia
GI	Black/Bloody Stools
CV	Regular Exercise
PULM	Hx Bronchitis, Asthma Or Emphysema
PULM	Recent URI
METAB	Excessive Perspiration
CV	Sleeps w/More Than 1 Pillow
GU	Menses w/in 30D
PULM	Clear Sputum Production
GU	Denies Possibly Pregnant

DOB:	06/12/46
DATE:	09/25/93
HT:	152.39 cm
WT:	66.81 kg
BMI:	28.76
BP:	120 /70
HR:	73 min.
HQASA:	2.0
VALIDITY:	GOOD

ALLERGIES

Non-drug allergies

SUGGESTED LABS

WBC	DIFF
PLTS	PTT
PT	LYTES
PROT	EKG
CXR	

MEDICATIONS

NSAID
Antacid Meds

PERTINENT ANESTHESIA CARE ITEMS

No Loose/Chipped Teeth	Previous Anesthesia
Neck Stiffness	?? FHx Bleeding Problem
Hx Snoring	Drink < 72 hrs
Caps or Bridge	

TOBACCO/ETOH/IVDA

?? Hx EtOH Abuse
Quit Smoking >2wks

The Pennsylvania State University
College of Medicine
University Hospital • Children's Hospital
Department of Anesthesia

Inter-office correspondence

DATE: January 20, 1995

TO: -Surgical Practice Site Medical Directors:
Fred Fedok, M.D.
Stephen Kahler, M.D.
William Parrish, M.D.
Robert Conter, M.D.
Stuart Goldberg, M.D.
Richard Pees, M.D.
Edward Schwenter, M.D.

FROM: Kirk Shelley, M.D., Ph.D., Practice Site Medical Director of Pre-Admission Center

RE: Introduction of the HealthQuiz device

I have already had an opportunity to speak to many of you in person regarding the Nellcor HealthQuiz device. This letter is a follow-up to that conversation and a chance to let those I have missed hear about it. The HealthQuiz is an innovative device being introduced by Nellcor. The HealthQuiz is a handheld computer driven questionnaire that allows the patient to directly enter their medical history. This is accomplished by means of a series of questions generated and guided by the patients demographics and answers to earlier questions.

The HealthQuiz should allow for significant improvement in our preoperative evaluation of the surgical patient. It is my pleasure to add that Nellcor has decided to declare the medical center a Luminary account for this product. This means that the medical center will be given 14 of these devices for free and support for at least one year without charge. In exchange we will have input into the evolution of this new device.

I am introducing this device with four goals in mind:

1) **Reduced cost of pre-operative testing.** After analysis of the patient's history the device generates a list of recommended laboratory studies. By basing these recommendations on the patient's history and not simply their demographics a significant reduction in testing is expected. As can be seen in one of the attached reprints a cost savings of $60 per patient has been reported in other institutions.

2)**Increased patient convenience.** The patient is also assigned a health risk index based on their history. Using this index it may be possible to offer the patient the option of forgoing the need of seeing an anesthesiologist until the day of surgery.

3)**Clinical research.** All patients answers are stored in the device for later retrieval. It will be possible to download all results into databases for later analysis.

4)**Improved patient care.** The HealthQuiz will ask all the 'tough' questions and never forget to cover an important topic. This makes it an excellent supplement to the 'free-form' data gathering technique practiced by most of our residents. From a medical-legal viewpoint it will be possible to prove that a patient was asked a specific question regarding their health and exactly what the patient answered.

The use of the HealthQuiz will represent a dramatic change from the way we are use to doing things here at Hershey. I plan a phased implementation with sufficient time and safeguards to allow the 'bugs' to be worked out. I would proposed that the logical place for the HealthQuiz to be located and used in the surgical clinics themselves. This way the HealthQuiz report with its recommendations will be immediately available at the time the pre-admission testing panels are being completed.

I look forward to our working together to bring this exciting new technology to the medical center. I will contact you shortly regarding the details of this implementation.

cc: Julien Biebuyck, M.B., D.Phil.
Thomas Krummel, M.D.

Mr. SHAYS. Thank you very much, Dr. Shelley.
Dr. Farrokh Alemi. Did I say your first name correctly?
Mr. ALEMI. Yes.
Mr. SHAYS. That's amazing.
Mr. ALEMI. Yes. [Laughter.]

As Dr. Shelley has pointed out, the real challenge ahead of consumer health informatics is not the technology. The real challenge is integrating this technology with health delivery systems. And there, I part with the rest of the experts here in asking for very specific help from the Federal Government. And I'll come to that point in a moment.

At Cleveland State University, I and colleagues provided computer services to different groups of patients, including the populations shown in exhibit 1 to my left. Although we served many different populations, what is unusual about our work and what is the focus of my testimony is the services we provided to inner urban, undereducated, poor patients.

Patients used their standard touch tone telephone to access these services. They did not need a computer or a modem. And these services were delivered to patients' homes. I think it is unusual to ask a patient to go to a library. Patients' lives are in real crisis. And if services are not delivered to their homes, there is no point in those services.

Exhibit 2 contrasts the types of services we provided with a typical Intranet or Internet service. Voice mail replaced e-mail. Patients asked questions about their health by recording them instead of typing the questions. Peer support was provided through voice instead of text bulletin boards. Patients responded to health surveys and decision aides by pressing keys on the phone pad or by recording messages.

Exhibit 3 shows patterns of use of our services. Poor, undereducated, pregnant, and drug using patients—these qualities were present in the population at the same time—were likely to use computer services delivered to their homes. The component patients were most likely to use was the bulletin board, where they talked to and learned from each other.

In addition, about half of the patients used the system to get information from health experts. Some in popular media claim that information services are likely to increase the gap between the poor and the rich, between the have and the have-nots. Our data do not support such fears. If we use our existing telephone technology today, the poor can and will use computer services made available to them.

The question then, is what good might come from such services? In one study summarized in exhibit 4, drug abusing pregnant patients who used the computer services more than three times a week were 1½ times more likely to be in drug treatment. Unfortunately, treatment was not effective, and the health status of these patients did not improve.

In another study summarized in exhibit 5, computer services did improve patients' health status. In this study, mothers of newborns were more likely to immunize their infants when the computer reminded them to do so.

In still another study summarized in exhibit 6, we compared voice bulletin boards to face-to-face support groups. Use of voice bulletin boards over a 4-month period led to 36 percent reduction in visits to physicians and 76 percent reduction in visits to other clinicians. These reductions occurred without a decline in the health status of the patients. The magnitude of these reductions surprised us. They seemed too good to be true. If they are true, here is a technological fix for a health care crisis.

Across all of our studies, a consistent finding has been that the computer services changed clinic visits. Sometimes, they increased them, and other times, they reduced the number of visits. Thus, computer service to the patients' home are an effective tool for managing the demand for health care. If this is true, then the technological solution for the health care crisis may be at hand.

If the technology is available and effective, you might ask, "Why do we not use it more?" There are many examples of health education campaigns carried out in this fashion, but we don't really have an example of these technologies fully integrated with delivery systems. Unfortunately, private investors are nervous about investing in technology based HMO's.

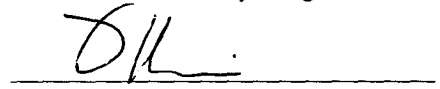
Twice, I have gone to private capital, and twice they have told me they will fund me as a software company, not as a health care company. First, they point to the traditional market risks. Then, they point out that the technology may not work when we go beyond scale of academic studies. Finally, they point to the extensive practice and organizational changes required to make the technology successful, a good example of which was given to you just now by Dr. Shelley.

These are not easy changes to bring about, and naturally, investors are concerned. Congress can change this by providing loan guarantees to investors that create technology-based delivery systems. I'm not arguing for grants or loans, but loan guarantees of the sort that you provide to several other projects around the world. Such guarantees reduce the risk and will allow technologically more efficient delivery systems to come to market and compete with existing HMO's. Thank you for this opportunity.

[The prepared statement of Mr. Alemi follows:]

Testimony On Computer Services To Patients' Homes
Presented to Congress of the United States
Committee on Government Reform and Oversight
Subcommittee on Human Resources and Intergovernmental Relations

By Farrokh Alemi, Ph.D.
Associate Professor of Health Care Management
Cleveland State University College of Business



On July 26, 1996

Thank you for an opportunity to summarize our findings concerning delivery of computer services to patients' homes. These findings are based on studies funded by National Institute of Drug Abuse, HUD, Center for Substance Abuse Treatment, Robert Wood Johnson Foundation, Cleveland Foundation and private organizations such as the Visiting Nurse Association of Cleveland. I should also disclose that I have a financial interest in the expansion of computer services to patients' homes, as I have started two private companies in this area - in one of which I continue to hold significant stock.

Through the studies I and colleagues conducted at Cleveland State University, we provided computers services to different groups of patients including the populations shown in exhibit one. Although we served many different populations, what is unusual about our work and what is the focus of my testimony is the services we provided to inner-urban, under educated, poor patients.

We provided computer services that were delivered through telephone lines. The patients did not need to have a computer or a modem to receive these services. There was no visual interaction, such as the kind of interaction one has while using Internet. Despite this limitation, the services we provided were rich and in some respect preferred to the type of services available through other mediums. Exhibit 2 contrasts the types of services we provided with a typical Intranet or Internet service. Voice mail replaced E-mail. Patients asked questions about their health by recording them instead of typing the questions. Peer support was provided through voice instead of text bulletin boards. Patients used decision aids and health surveys by pressing keys on the phone pad or by recording messages. One unique aspect of telephone-based services is that patients are called by the system while Internet and Intranet services need to wait for the patients to initiate the interaction.

Exhibit 3 shows pattern of use of our services. Our experience showed that poor, under educated, pregnant, and drug using patients were likely to use computer services delivered to their homes. The use of voice mail was not surprising, because the computer called the patients' home and encouraged them to participate. But the use of other components required patient's initiative. The component patients were most likely to use was the bulletin board, where they talked to each other. In addition, about half of the patients used the system to gather health information from experts. I have read in the popular media claims that information services are likely to increase the gap between the poor and the rich, between the have and the have-nots. Our data do not support such fears. Our experiences proved that this need not be the case. Any where there is a telephone, we can deliver computer services. If we use our existing technology, the poor can and will use the computer services made available to them. The question then is what good might come from use of these services?

According to our studies, the impact of home computer services on patient's health is mixed. In one study summarized in Exhibit 4, drug abusing pregnant patients, who used the computer services more than 3 times a week, were 1.5 times more likely to be in drug treatment. The technology was successful in bringing patients to or keeping patients in treatment. Unfortunately, among the patients we studied treatment was not effective and the health status of the clients did not improve significantly. In another study summarized in Exhibit five, the use of computer services to remind mothers of newborns at an inner city urban clinic led to increased on-time immunization of the infants. This was one of the only studies done by us in which the use of computer services led to improvement in health status of patients.

In contrast to the mixed result on improvement of health status, there is a growing and consistent evidence that home computer services are likely to change utilization of health services. We have already mentioned that the use of computer reminders led to more well child visits and more treatment participation. In another study summarized in Exhibit 6, we found that use of voice bulletin boards over a 4 month period led to 36% reduction in visits to physicians and 76% reduction in visit to other clinicians. These reductions occurred without deterioration of the health status of the patients. The magnitude of these reductions surprised us but are similar to savings reported in studies in Wisconsin and in Vermont. For example, in a randomized clinical study investigators found that when physicians called the patient instead of scheduling a follow-up visit, there was a 28% reduction in total cost of care without any deterioration in patients' health status. These are not small reductions. If these findings can be replicated and generalized to other chronic illnesses, then a solution for the cost crisis is at hand. Here is a technological fix for the rising health care costs.

You may wonder what is the reaction of clinicians to these innovations. Home computer services change not only the patients but also the clinicians. In a study conducted by Shirley Llorens, a doctoral student, the computer interviewed the patients prior to a visit and sent a facsimile to the physician. During the visit the physician reviewed the facsimile. Data showed that as a consequence of computer interviews the detection of chart

documented alcoholism increased by 8 fold compared to historical levels. Surprisingly, the majority of the 40 physicians involved preferred this method to directly interviewing the patient. A number of studies conducted by others show that patients' are more likely to report deviant behavior to a computer than to a clinician -- presumably because the computer does not judge them. So, here is a technology that both patients and physicians prefer, that can enhance the relationship between the patient and the clinician and we know it could reduce cost of care without deteriorating health care quality. It seems like a godsend.

Why then, you might ask, do we not see large scale implementation of these technologies. There are many reasons. Some health care providers have not heard about these findings. Others do not believe it. Perhaps additional studies can confirm these initial studies. But at one point, you have to stop studying and act on the findings. For these studies to translate into actions, the industry needs examples of companies who have done so and succeeded. When such technology based HMOs enter the market, they increase the pressure on other HMOs to adopt these change or loose market share.

Unfortunately, private investors are nervous about investing in technology based HMOs. First they point to the traditional market risk. Then, they point that maybe the technology cannot work when we go beyond the scale of academic studies. Finally, they point the extensive practice changes required to make the technology successful. Success, for example, requires:

(1) re-thinking the relationship between patient and provider,
(2) asking for and helping chronically ill patients to take care of themselves,
(3) changing the notion of primary care doctors as gatekeepers in managed care settings and allowing patients to see specialists based on triage protocols,
and finally (4) reducing the emphasis on centrally located large clinical offices.

These are not easy changes to bring about and naturally investors are concerned.

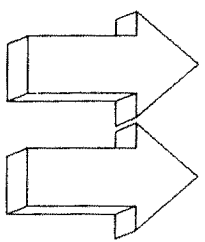
The government can encourage private investors to get involved in demonstration of new health delivery systems. Congress passed a program to set up new infra-structure for information sharing. This is not enough. We do not need software, we need new delivery organizations. What we need is to take these software programs, put them together with teams of clinicians and begin to serve patients and employers. It will be useful for the government to provide loan guarantees to investors that create these types of delivery systems. I am not arguing for grants or loans, but a loan guarantee -- of the sort that we provide to several other projects around the world. Such guarantees reduce the risk of investing in entirely new delivery systems and will allow technologically more efficient delivery systems to come to market and compete with existing systems.

Thank you for this opportunity to provide this testimony.

Exhibit One:

Populations Served

- Patients with CHF
- Patients with HIV
- Care givers of schizophrenic patients



- Teenagers in housing projects
- Drug using pregnant patients

Exhibit Two:

Same Services, Different Mediums

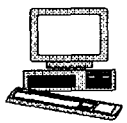
	Connect	Internet
Equipment	Phone only 	Computer+ 
Messages	Voice Mail	E-Mail
Health Advice	Recorded Q&A	Typed Q&A
Peer Support	Voice bulletin	Text bulletin
Assessment	Press phone keys Recorded answers	Typed
Alerts	Yes	No

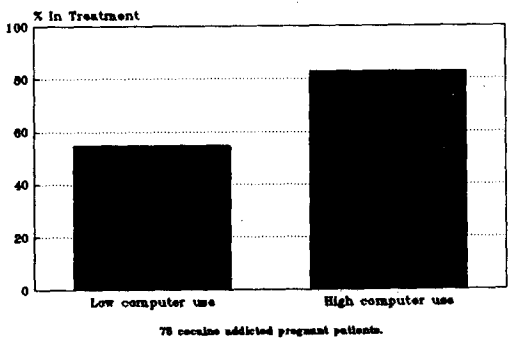
Exhibit Three:

Use Of Computer Services

	Use	Weekly Avg
Voice Mail	87%	2.3 times
Q&A about health	45%	0.2 questions 1.7 answers
Electronic support	96%	2.2 times
Health assessments	49%	1 time

Exhibit Four:

More went to treatment ...



but no effect on drug use.

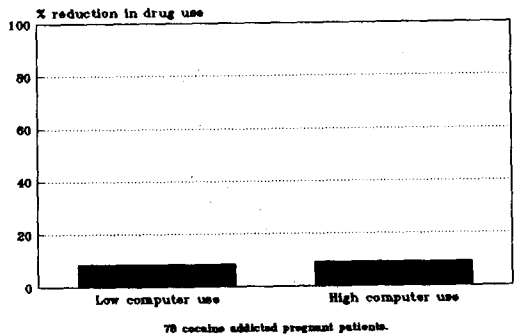
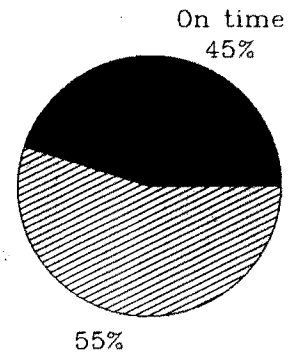
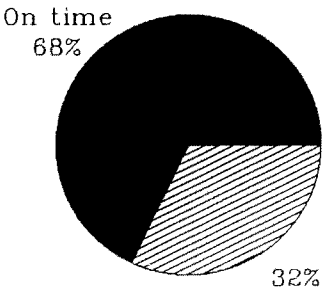


Exhibit 5:
On-time Immunization Improved



No reminder

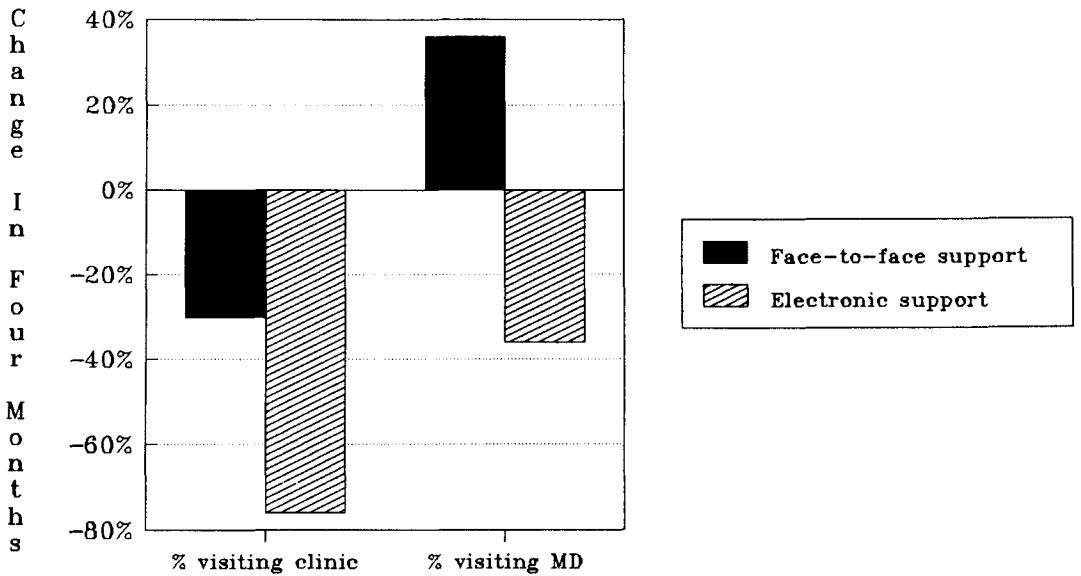


Computer reminder

Based on CDC criteria. Subjects were 196 mothers showing at pediatric clinic. Both groups were matched at base-line.

Exhibit Six:

More Computer Use, Less Visits



Subjects were 53 drug using or recovering mothers. Matched random assignment to groups.

Mr. SHAYS. I'm not going to ask you to answer this question now, but it would strike me—and then I would love everyone to respond—it would strike me that if there are savings to be made, you don't need the public sector to get involved. I would love to have that dialog. I mean, the fact that you encounter failure is, "Welcome to the real world." But it will be interesting to have that dialog.

Mr. Wasow.

Mr. WASOW. Thank you.

Mr. SHAYS. I'm going to ask you just to push the mic down a little bit. That way, we'll get your voice better.

Mr. WASOW. Technology failure.

Mr. SHAYS. No, no.

Mr. WASOW. Again, I, like the other panelists, I would like to thank you for inviting me here. It's a real honor to be here. I was once an intern in Rayburn, and so it's a special honor.

Mr. SHAYS. Well, it's an honor to have you.

Mr. WASOW. Well, thank you. I also feel like a child among elders here. I am the son of a doctor and the grandson of a doctor but not a doctor myself. So it's with great respect that I have for the other people that I'm pleased to be here.

I would like to begin, again, by introducing myself. My name is Omar Wasow. I'm the president and founder of a small company called New York Online. And we are an online service that is like a small America Online based in Brooklyn, NY.

I would like to talk a little bit about how I got started just as an introduction. I spent a year in a program after college trying to get ex-drug dealers to start legal businesses. This was a job training program. And after teaching entrepreneurship for a year, I really wanted to start my own business and was particularly interested in the idea of a cafe.

And so I looked into that. I did a lot of research. I had been saving money for a couple of years and realized that a cafe was out of my league, it was just not something I was going to pull off. But having played with and had a real passion for computers for many years, I thought maybe I could start sort of an online cafe.

And the idea there, which I think is a little different from what we see typically represented in the Information Superhighway, is this idea of a place where people are talking to each other. We have heard from a number of the earlier panelists that the most successful components of these health care delivery systems was the place where people could talk to each other.

On America Online, I know that about 80 percent of the time people spend on the service is spent communicating with other people. The example was just given that the most popular part of this other technology was the place where people could provide information to each other.

And that was the heart of my concept behind New York Online was that I was going to create an online community, a place where I wasn't trying to publish to an audience, where I wasn't trying to be the voice of authority, but rather I was going to facilitate conversations. And that clearly has—I mean, I would like to begin by talking about in particular about one member of this service, and this is just an example.

And it's clearly anecdotal, as opposed to the various substantive evidence that has been given prior. But we have one member who was an Ivy League trained lawyer and for the last 15 years has been suffering from multiple sclerosis. He in the last 5 years in particular was sort of in a rather extreme state of suffering and hasn't been able to get out of his home much and in particular hasn't been able to have substantive conversations with other adults, because other adults are so put off by—or not even put off but just sort of thrown by his physical appearance that it's very hard for him to engage in kind of meaningful conversation.

He has been on our service now for 1½ years and spends hours on the service and is absolutely delighted by not just the opportunity to engage in conversation, but to really engage in substantive, meaningful, intellectual conversation with other people from his home.

And not only that, people who he meets online come and visit him. Some of the people who are on staff at New York Online, some of the friends who are part of this extended community are now friends of his. And because the initial barrier of sort of physical appearance was not a barrier to initiating a friendship, relationships were established.

So clearly, there are a number of very useful things here in this community model for improving the quality of delivery of health care to people. It breaks isolation. If somebody is alone in the home, people who suffer from common illnesses who have common frustrations are able to meet, even if they're dispersed across broad geography. It serves the homebound.

It also democratizes access to information. I mean, in particular around this idea of, I'm not the authority talking to other people, just like I'm not the doctor telling you what's right or wrong; in many cases, people who suffer from some illness know as much about that illness as many doctors and are in a much better position to share information with each other than any kind of official body, which is not to say that official bodies and authority figures aren't important, but that there's a very important supportive and facilitating role there.

And then this last piece that I talked about about how this particular client subscriber has now an extended group of friends, there's an author at Harvard who wrote an essay called—a text called "Bowling Alone," which was talking about how there's a very high correlation between the quality of a democracy—he was measuring democracies in Italy, I believe—with the amount of participation in civic organizations and that if you—that there's a very high correlation between people participating in church groups and in PTA's and these kinds of things and the quality of the democracy in that region and that according to his data, there has been a significant decline of people participating in civic institutions, civic organizations in this country.

And part of what I believe is happening with services like New York Online is that there's the potential to break that trend and that people who may be retreating into the home are now being drawn out.

Sometimes, people have asked me, "What does it mean if people are just spending more time in front of a computer and less time

with friends?" And my argument is that people are not spending less time with friends, they're spending less time with television. They're spending more time communicating and more time interacting and interacting across lines of race and class and culture and physical disability that doesn't happen in real life, and that's quite inspiring.

In closing, I guess I—not being a doctor, not being somebody with an institution behind me, I have sort of a different approach to perhaps what the Federal Government could do. I really come here as an entrepreneur and as somebody who sort of runs a seat-of-the-pants operation very much from a kind of grass roots perspective, where we have a—we are run out of a small office in Brooklyn.

And my fears are less that the technology will not reach people, because I've seen in the last 3 years, which is for the most part, a small period of time, an astonishing rate of innovation and a level of change and improvement that is just awe-inspiring.

There's a law in the technology world called Moore's Law, which posits that every 18 months, the cost of a microchip will cut in half, or its amount of power will double. And we have seen that now for the last 20 years, and it's likely to continue for the next 20 years. And so I actually don't worry that poor people will not have access to the technology. I don't worry that this will not become a widespread medium. I think it's happening at an incredibly fast pace.

I think what does need to happen is that we allow for that innovation, that there be more competition, frankly. The telephone service I get in New York is, to be polite, substandard. And I'm spending a lot of money on telephone service. And there's no reason why I should have squirrels eating through my phone lines every 6 months. But that's neither here nor there.

And I guess the other thing to my mind that I see as sort of a lesson of the technology and something that really inspires me is that we are moving into an economy where the technology will be widespread where essentially, information will be the primary determinant of your ability to earn an income and that that will be available to anybody with a good education and that whereas in an industrial economy, where land labor and capital determine wealth, in the information economy, education determines wealth.

And therefore, the most important agenda before us is ensuring that poor people are given access to good, quality education and that that is what's going to increase access to technology and that that's what's going to increase the quality of information available to people. And to my mind, you do that with vouchers.

[The prepared statement of Mr. Wasow follows:]

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Superhighway or Supper Cub?
health informatics from the view of a community oriented online service

by Omar Wasow

From Al Gore to Ziff-Davis, no one can stop talking about the information superhighway. Corporate titans are proposing mergers, the government is legislating new industries into existence, and private citizens across the globe are getting wired. Yet amid the buzz a consistent misguided assumption underlies most blueprints of the digital frontier: the idea that *information* is what makes this new medium thrilling. Most of the news about the information superhighway has missed its true potential as a community building tool. The very name "information superhighway" emphasizes the value of accessing static data rather than plugging in to people. Community oriented systems, in contrast, can provide dynamic, engaging, educational experiences that people return to again and again.

One way to think about the difference between information based systems and community oriented systems is to look at how people learn. In the summer after my sophomore year of high school I spent two wonderful months living and traveling around Mexico. Though my Spanish fluency was limited at the time, over the course of those few weeks my speaking skills improved dramatically. When that summer ended I returned back to school and promptly began to forget much of the Spanish I'd learned in the local culture and community of friends and acquaintances. Ever since then I've been convinced that the best way to learn a language was to go live in a country where its spoken. Textbooks and teachers were no competition for total immersion.

Similarly, online systems are superb for distributing information, but most of us already have too much information and get bored quickly by endless streams of data. In one example of a venture built around the information model, Sears and IBM joined forces in the late 1980s to build a new "network for active minds" in an online computer service named Prodigy. One in-house analyst prophecized that "its not a question of will this

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make money, but rather how much." In the intervening years, however, Prodigy only lost money and tons of it. Prodigy imagined that by combining encyclopedic quantities of information like news and weather, with traditional advertising they would have an unbeatable product. What the folks at Prodigy did not understand is that most folks don't read encyclopedias. By the time they realized this simple fact, they had already lost millions and millions of dollars and they are only just now beginning to adapt to a more community oriented system.

In addition to providing information, online systems are also superb at providing people with a network of friends with whom to share their busy, often isolated lives. In contrast to Prodigy, another national online system called America Online has been growing profitably — faster than it can manage — by creating a system where the primary content is the other people online.

As part of creating networks of friends and acquaintances, community oriented systems can also be used to improve the delivery of health care services. Online systems with strong local cultures and lots of people interacting are excellent for integrating diverse populations and stimulating people intellectually.

With the democratization of cyberspace comes a new possibility to build linkages and friendships across socially disparate groups. Historically cyberspace demographics have been fairly narrow and homogenous. What was once an elite collection of techno-privileged men, however, has recently become a far more diverse and democratic universe. As the technology required to participate in cyberspace has gotten cheaper, and more accessible, telecommunications has gone to the masses.

One benefit of the medium is that all interactions are textual and consequently people who might hold prejudices or preconceived notions about one another can initiate dialogues before their superficial biases, for example around handicaps, come into play. Another advantage of the medium is that individual members of a community who may live in different neighborhoods, hang out with different people and work in different fields can meet and develop relationships online. As a result, social cleavages that in real life tend to cluster everyone into their own separate cliques begin to break down.

Almost by definition, community oriented services focus on communication and, due to the nature of

the medium, written communication. As a result, anyone active on a lively, thoughtful service will find themselves writing a lot, whether its personal electronic mail, live chats among a handful of people or public messages read by the entire community. For people who might be home-bound and lacking thought provoking interactions with others, online services can be critical. This is most obvious with public messages, but is also true of e-mail and chat. With public conferences, any number of people participate in discussing a particular topic. Individuals post messages with their opinions of the particular topic and over the course of hours and days those messages are replied to by others. Each of these often informal, written interactions sustains typing, reading, writing and critical thinking skills.

In closing, an integral part of the future of cyberspace lies in systems that focus on people communicating with people. Information will continue to be an important component on the superhighway but most of us are already overloaded with data. We are social creatures in search of friendship and we tend to live and learn with greater ease and pleasure when that basic human need is nourished.

Omar Wasow, president and founder of New York Online, was named by *Newsweek* Magazine's article "50 for the Future" as one of the most influential people to watch in cyberspace. Wasow is also a member of the Samsung Braintrust and a commentator on MSNBC.

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Health informatics via the Superhighway or supper club?
the view from a community oriented online service

- Content not content
  - health information abounds, what we are looking for is relationships
  - relationships between facts, ideas and opinions ... insight and trust
  - relationships with people

- New Media, New Journalism
  - evolving role of the journalist: both an expert informing a community and a participant being informed
  - with many health issues, sufferers of illnesses are as expert as many doctors
  - audience can inform each other

- People are cheap, Editors expensive
  - creating fresh editorial every day is very costly...
  - unless subscribers inform each other.

- On the Web, no one can hear you scream
  - People turn to online communities to break a sense of isolation, be it geographic, illness related or otherwise
  - What do telephones, beepers, cellular phones, answering machines, faxes and e-mail have in common? They're almost always about people communicating with people.
  - 80% of time spent on AOL by subscribers is spent communicating with others (email, chat, conferencing). Prodigy nearly died as an information focused system.
  - nothing is more dynamic, complex, unpredictable and engaging than another person.

- The online Killer App: e-mail
  - the feature that compels people to log in again and again is email
  - most versions of Web servers don't offer it
  - at the heart of community based services

- On the internet, no one knows you're a dog
  - physical disability, in many cases, ceases to be an issue
    - discuss NYO members
  - playing with identity hugely popular (age, gender, profession, interests)
  - at the same time, the possibilities can be abused so people eventually want some boundaries and accountability... hence the desire of smaller, more intimate online communities.

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Mr. SHAYS. Thank you very much for your testimony. I would like to just quickly get a sense of whether each of you think of yourselves as entrepreneurs or academicians or practicing medical doctors. Because I want to know which way you got into this.

Dr. DOUMA. At this point, I'm an entrepreneur, medical director, CEO of a small business.

Mr. GUSTAFSON. Academic researcher.

Dr. SHELLEY. In this context, a practicing physician.

Mr. ALEMI. I am both, academic researcher and an entrepreneur.

Mr. SHAYS. But which came first?

Mr. ALEMI. Academic research.

Mr. WASOW. I think I'm an entrepreneur aspiring to live up to the standards of my parents and be an academic. [Laughter.]

Mr. SHAYS. You were talking and thinking of the infinite possibilities of the field you're in. When I started in 1987, there was a young man just out of graduate school who was campaigning with me. And he said, "If you lose, I would like you to go into this business I'm starting." And he was trying to deal with the year 2000 when it becomes zeroes, and zeros say it's 1900 instead of the year 2000.

He came and visited me a month ago. I said, "How are you doing?" He said, "I'm doing OK." He said, "My stock went up," and he described it. And I said, "Well, how much are you worth?" He said, "$220 million." It's the first time I wish I had lost the election. [Laughter.]

Mr. TOWNS. No, then I would be Chair.

Mr. SHAYS. You could be Chair, and I could have a few million. No. Let me—but this is—what's exciting, though, what we're dealing with is how much does this incredible competitive environment shape what happens, and where does the Government step in?

And my sense is, as infrequently as possible. But we're dealing with very, in some ways, sensitive issues that if not disseminated properly, could be a—not catastrophic, but harmful.

Dr. Shelley, I saw what you had as very simple. It seems to me so logical. And yet you pointed out there was one test you didn't do, you didn't test it with the doctors. But then I think of the axiom that basically, most successful businessmen and women, they're the second one into the field, not the first. They let the first make the mistakes.

So I think, Dr. Alemi, I am troubled—not troubled, but I have to wrestle with when would the Government logically come in? Because I think there's so much money to be made. And I mean that in a positive way, where people save money, and they benefit from the savings.

They save everybody money. So define for me when you really think that the market simply won't allow for the kind of innovation and creativity needed. And then I would like all of you to respond. I would like fairly short answers collectively.

Mr. ALEMI. We are really talking about apples and oranges here. Many people point to the success of the information technology and the spreading of the technology. But there is no—to my knowledge, there is no health maintenance organization which is really based on these technologies, because there is a lot of practice changes

that must happen. These are not technological changes that are required.

They're organizational changes. And the way people practice medicine and the way—for example, HMO's will not need as many buildings. So existing HMO's cannot take advantage of these technologies the way they should. These are examples of why these HMO's are not proceeding. Another example is——

Mr. SHAYS. No. What I'm going to say, though, and then I'm going to ask others to respond, is that your implication was that because of failures, the Government steps in and helps a struggling company through research or financial assistance. That's what I was hearing you say.

Mr. ALEMI. No.

Mr. SHAYS. OK.

Mr. ALEMI. What I am asking for is a loan guarantee so investors can say, "Sure, there's a lot of risk here, but we are going to put our own money and go ahead with this," because there is a lot of risk here. The technology has been proven. A lot of organizational and practice issues have not.

Mr. SHAYS. Let me just say this to you. The only way I would want that is if because there's so much risk, nobody wants to get into it. But I think people in this world are going to take the risk, make the potential money, or lose the money. I would love others to respond. I would just say, what I've noticed—and I've really gotten into the health care area significantly.

Since, frankly, the President put it on the table, I mean, if nothing else, he just forced all of us as Members of Congress to increase tenfold our knowledge and so on. But what I've learned is that doctors were not taught to be business men and women. They were taught to be doctors. And immediately, they're the primary small businessmen.

I think, of the primary physician. They're small business men and women with people coming in and out and making money and staff and all the Government redtape. And they don't like that part of the job, many of them, and they weren't trained for it. And so I'm thinking that here you've got someone who's thinking in terms of—I'm sorry my question's so long, but the observation is where I would like the comment.

Because it's fascinating. I love it. You have someone who's kind of thinking differently because he didn't spend all his time thinking in terms of being a doctor and so on. So if you could just respond, and then I'm going to give it to Mr. Towns.

The question is, doctors get very angry that the insurance companies and people who don't have an "M.D." behind their name and a "Doctor" in front are basically determining what happens in health care. Yet I submit that they weren't given that kind of training, and they haven't been able to seize the opportunities.

So what is my question? My question is this. How is the medical community interfacing with the entrepreneur? That's basically it. It took me a long time to get to it.

Dr. DOUMA. I'll be glad to respond. I actually was trained as a physician and was practicing for 10 years prior to becoming—I actually worked—you weren't here when I presented. I worked for a

major corporation, including an insurance company, and now I'm an entrepreneur.

And I guess I think what the Government's role can be is not in the subsidy in a typical sense, but intellectual subsidy. Physicians are, I think, in the most awful position in our society in that we create myths. And the medical profession has certainly perpetuated the myths of demigods. And we're not. No one has ever been.

And we have created that relationship with our patients, as well as society. So when we're in that position, it's more difficult to change, regardless of whether we were trained one way or another. And so physicians are not going to be our change agents. I early in my career coming out of a fellowship actually in looking at health communications for 2 years—I went to the American Medical Association, and in order to change my own profession.

And as I was naive at the time—I don't think physicians are going to be in a leadership role, not because I don't think they're doing, obviously, damn good work. I think what's going to make the change is going to be at a more societal level.

And I think that's where the Government can function, particularly as a large insurance company that the Government is, in working with other insurance companies and in working with other organizations that have a tremendous need to improve quality and maintaining costs. And it's through the persuasive power of the Government, the communication power of the Government on those economic forces, bringing them together—I know in your district in Connecticut—in fact, I used to have an office in Connecticut—there are a lot of folks who would love to sit down with you, I think, and hear about what you're trying to say.

At the same time, I would like to add that one of the major problems that physicians are concerned about is loss of the patient. And you hear that in the context of self-help and information. And quite frankly, it's the reverse, that one of the things we can do is to bring the patient back to the physician through informing the patient, empowering the patient to talk to the doctor.

We may have some ramifications on that in that you can no longer take 5 minutes with a patient. You may have to take 10. And perhaps we're going to have to figure out delivery systems. And I think what we heard before is, some of those delivery systems are providing the information not out of the doctor's mouth, which is a too costly mouth to support, but out of a medical delivery system that is influenced by that physician. Long answer. I apologize.

Mr. SHAYS. Doctors clearly are changing, a lot of them are, and they're responding quite often to change. It blows their mind. They spent a fortune to get their degree, and all of a sudden, the world has changed so dramatically for them.

Dr. DOUMA. Yes.

Mr. SHAYS. Dr. Gustafson.

Mr. GUSTAFSON. Well, change comes slowly. And I think that we need to recognize that.

Mr. SHAYS. To whom?

Mr. GUSTAFSON. To virtually anybody and to anything. It's not easy to make a change. We know that successful change starts with innovators, people that like to try new things. They try it out.

Then the people who really lead the thinking of a field watch what happens as the innovators try. And they eventually either come on board or they don't.

What we have done with CHESS has been to take the philosophy that we need to go to the innovators first. So we have formed a research consortium of seven of the most innovative health care provider organizations in the United States, Hartford Hospital being one of them, Harvard Community Health Plan, Group Health Puget Sound, and so on.

These organizations are using CHESS in a variety of ways and are learning from those experiences. And now so instead of us just publishing our results, what we're finding is that Health Partners in Minneapolis is writing articles about their experience with CHESS.

London, Ontario, Regional Cancer Center is writing articles on their experience with CHESS. And we believe that over time, the slow dissemination of CHESS through these key innovative organizations will lead a larger proportion of medicine adopting it. I just think it takes its time. We can only go so fast with change. We need to lead with the innovators first.

Mr. SHAYS. Dr. Shelley.

Dr. SHELLEY. As I said before, we live in a time of tremendous change, and an impossible to predict outcome of managed care. It's clear physicians have lost autonomy and are in a state of shock. I've come out of a large academic medical center that's really reeling from the loss of income and the ability to function with autonomy.

At the same time, the question is, what's the role of Government. I think that it was sort of implied in the question I heard—and you might not like this answer, but from my perspective as someone who is coming in from outside of Washington—how can I say this? You people went broke about 5 years ago and haven't realized it yet. And you're going to be pretty busy trying to manage the resources of the Government over the next 10 years.

I think you have an advantage and in this particular area, I think the private forces are going to be moving for you, and you're not going to have to dabble very much. I think there are certain safeguards the Government needs to watch out for, which I think is its appropriate role, that of privacy, as mentioned, that of consumer protection. I think that that's not unreasonable—for the most part, it's a sort of "Get out of the way" sort of attitude.

And I suppose you might consider me sort of biased in this. The marketplace will sort this out. And the doctors will work with the private sector—it's Dr. Roizen working with Nellcor Corp., saying, "I've got this great idea." Nellcor buys it, tries it, it fails. It's a little bit like Thomas Edison when he was asked how he felt after 3,000 failed experiments to make an electric light bulb. And he said, "Now, I know 3,000 ways not to make a light bulb." It took another thousand, and he got a light bulb.

And we're going to see this continuous process of experimentation and failure, experimentation and failure. And often, the innovators are not the ones who make the money in the process. So that sort of sums up my bias.

Mr. ALEMI. I think if you want to go beyond health education and consumer education, you need to make major organizational changes in HMO's. For example, the whole notion of gatekeeper, primary provider, does not fit within these technologies. If you can triage the patient directly to a specialist, that's the kind of innovation that needs to happen. That level of innovations will not happen unless somebody can produce a new kind of HMO into the market. And that's the difficulty. Those organizational changes remain a difficulty.

People have adopted our systems. Visiting Nurses Association of Cleveland has fully adopted our systems. But they're still practicing in the old way. They are using the technology but using it in a way that I can see through and say, "There's a lot of better ways of using this technology."

Mr. SHAYS. Thank you.

Mr. WASOW. I guess—I mean, again, as an entrepreneur and as somebody who's not a doctor, I have something of a bias and something of a naivete about it. It seems to me if you have this kind of broad-based market failure, that in many cases, that market failure is a function of kind of interventions that are tax policy and sort of regulatory structures that oftentimes block innovation.

And I think it's true that we live in a world where things don't change fundamentally, but I know the industry I'm in has, again, just an astonishing level of innovation. And it's one that would not happen but for the kind of free-for-all that's happening.

And while I agree, I think the other point, though, that was made that's really important, on issues of civil rights and civil liberties, I think the Government has a very important role and that on consumer privacy, that's critical.

Mr. SHAYS. I'm going to give the floor to Mr. Towns. He has been very patient, and so has Ms.—she was patient and left. [Laughter.]

I do want to say that I do notice that our witnesses from the first panel are still here. At the end when this panel's over, if you want to make a closing comment based on comments you heard, to put it on the record, I'm happy to do that. It's not required, but if you want to.

Mr. Towns.

Mr. TOWNS. Thank you very much, Mr. Chairman. And I really appreciate you spending the time, because this is very, very interesting. What I would like to do is just sort of ask some "Educate this Member" kind of questions. I'm very interested in what's going on here.

I guess to all of you, I would like each of you to describe briefly what it cost and how long it took to develop your system. And start with you, as brief as you can.

Dr. DOUMA. Yes. Mine is a little bit different in that I operate on part of the America Online Network. And as an entrepreneur, it took us 4 years and bootstrap money and no investment, et cetera.

But we were building on a large platform, which took a few hundred million dollars to develop, which is America Online. But it's now—again, it's a system that's delivering to 6 million homes. And the marginal cost to grow is a lot less. But it took 20 years of intel-

lectual sweat equity in order to get here. But I don't know what that's worth.

Mr. GUSTAFSON. CHESS was developed over a 5-year period with a grant from the Kellogg Foundation. The grant from the Kellogg Foundation totaled $2 million.

Dr. SHELLEY. I understand from my conversations with Nellcor, they have invested approximately $10 million in this particular project so far.

Mr. ALEMI. Connect System was developed with a grant from the National Institute of Drug Abuse for $3 million, as well as grants from Johnson Foundation, Center for Substance Abuse Treatment, and Cleveland Foundation and Visiting Nurse Association of Cleveland.

Mr. WASOW. I think I lose this. I committed about $100,000 for 3 years.

Mr. SHAYS. Was that your own money?

Mr. WASOW. Yes. It was savings and——

Mr. SHAYS. Well, I think that's something.

Mr. WASOW. And VISA. I have to thank VISA. [Laughter.]

Mr. TOWNS. After all, Mr. Chairman, he's from Brooklyn. That's expected.

We talked earlier about insurance companies and HMO's saving money and those savings stimulating the growth of these services. But the greatest needs often do not have health insurance and get most of their health from public hospitals. Where does the investment in these people come from?

Dr. DOUMA. I would be glad to answer that. I think public hospitals are one of the most inefficient delivery systems I've ever seen in my life and that the investment, if we really look at it, the question is what bottom line do you look at, we can have dramatic impact on the cost of the delivery of the medical services that today are delivered which, unfortunately, I think, are not the quality that any of us in this room think it should be.

So the cost comes out or the savings come out of that delivery system. The challenge is, who has the responsibility, authority, and the power to move dollar X from A to B in order to show a savings.

Mr. TOWNS. Thank you.

Mr. GUSTAFSON. Our experience has been that Medicare is a possible source of funding for these. The peer review organizations within HCFA are taking on a new beneficiary outreach role now that they haven't taken on in the past. And one demonstration project that we're engaged in right now involves the peer review organizations in disseminating CHESS to elderly women with breast cancer in the Madison area.

So I think that Medicare and peer review organizations have a role in this. Medicaid may also have a role in this area, too. As we're able to demonstrate the potential cost savings of programs of these types, it seems to me that as a primary payer of health care for the poor, that we might find Medicaid being a source of funding.

Dr. SHELLEY. And speaking for the academic centers, they're often the ones that sort of step into the fray. Academic physicians often accept a lower salary and have residents that overwork and work for the indigent population extensively.

Go into any major city, and you'll find these large medical centers. And some of those are teetering on the edge of nonexistence. So that's where some of the public dollars may have to come from to help support these indigent populations.

Mr. ALEMI. As you mentioned, Medicaid HMO's are using these systems. They are clients of TelePractice and are paying for these services. But the question remains for people who don't have insurance. In Cleveland, Metro Health System, which is a county hospital, is using these services for managing their own patients.

In addition, we have in the past worked with HUD to provide these services to housing project residents, which looks at not just patients, but whole communities of people who are living together. These information services can be provided to large groups of people in entire communities—the only problem is integrating these information services with health delivery systems.

Mr. WASOW. And just simply, I would say—I mean, I think the Government absolutely has a role to play in subsidizing access to health care for poor people but that people have to be in a position to make considered decisions about whether they want to spend x number of dollars to get it face-to-face or get it over a computer and that right now, you've got a health care system that really doesn't allow for considered choices and for people to make market decisions that say, "This is worth 50 bucks to me, or this is worth $10,000."

Mr. TOWNS. As experts and developers, what can you do to increase access to health information systems by those who may lack computer equipment or be uncomfortable using them?

Dr. DOUMA. Let me answer that in the editorial "we" rather than me as an individual, because I guess I firmly believe that collectively is the answer to this. I think there are several different things that can be done. One is certainly to educate and train people to be able to use the computers in the first place.

And without that, you're not going to—no matter what else you do, you're not going to get beyond the barriers, whether those are disadvantaged people because of education or whether it has to do with folks who are computer disadvantaged because they're much older than most of us and they just didn't have the opportunity.

And then once that's done or a part of in parallel, is that we look to provide access in community locations. And whether that's the private sector, the doctor's office, or whether particularly the public sector, schools, libraries, community health centers, and they're—it's again, I think, we would like to motivate whoever those folks are in those centers to use these as services, not necessarily that we have to come in with a separate Government program to subsidize them.

And finally, I think that the private sector—and in hearing Omar talk about this, all of this is going to "come out in the wash," so to speak, in 10 years when the cost of connectivity goes down to, I don't know what his guess will be. At this point, it will be 10 cents. But——

Mr. WASOW. They'll be giving it away.

Dr. DOUMA. That's right.

Mr. WASOW. What's the cost of television?

Dr. DOUMA. Well, we may in fact end up with the model of the cable model of a sorts or the public television. It's incredible the opportunities. But let me go back to where I started.

What we need to do, I think, is to educate all of us, including especially the general public, including especially those who are more disadvantaged, that this is an important public health message. And out of that will come as many of the answers as we can sit here and define or design ourselves.

Mr. GUSTAFSON. Well, I think that we found because our focus on CHESS is dealing with people in crises—breast cancer, AIDS, so on—we found that because this is a time of crisis, it's also a time of change for these people. And we find that people worked very hard to get the information and support they need to deal with something that is dramatically affecting their lives.

We need to obviously create these systems in such a way that people with relatively low education can use them. CHESS is set up to be used by somebody with about a seventh grade reading level. But we found when people are under levels of tension and stress like they are, that people are willing to work very hard to learn how to use systems of this type. And we're finding people even with third grade educations can use it.

Second thing is, I think we need to be sensitive to the fact that there are different languages out there to more and more extent, and we need to be able to respond to that. And that means that we need to be, for instance, providing systems in Spanish, as well as in English. But here, we have a real question:

And that is, how much of a change do we have to make in the system in order for it to be effective. Do we need to just simply make a literal translation into Spanish? Or do we really have to go as far as making also recognition of appropriate kind of cultural differences, such as in nutrition and food? So we really don't know how far we have to go in the language thing.

The third thing is that I think we need to do a careful job of thinking through how to train people to use these systems. We have found in CHESS, for instance, that the people who benefit from CHESS the most are not the people who use it the most. They're the people who use it the most intentionally, so that a person comes in, they're worried about pain, they go into the instant library articles, and they read articles on pain.

Then they go to the questions and answers and read stuff on pain. And then they go ask a question in the discussion group on pain and get that going. But we need to know more about how people benefit the most from these systems, and that's another reason why we need evaluation in these areas. We don't have the full answer to these questions.

Mr. TOWNS. Thank you.

Dr. SHELLEY. I would say that it behooves the developer to make sure that they put in standardized, user friendly systems. And our population is going to be quickly educated to certain paradigms. The remote control we all use on the television is a roughly new innovation, but it's a rare person in our society who can't figure out how to use that. And I believe the Web is also demonstrating a similar standardization of hyperlinking and how information can be interconnected.

One of the things I think that was most innovative about the Health Quiz device, and why I was so drawn to it, was simplicity. It had four buttons on it, and that was all. And I'm able to give it to fairly elderly patients, and they can quickly figure out how to use this. And also, it was back lit so that it was easy to read.

And it was a very rare patient I would find who could not use it, although I do remember quite well a 25-year-old gentleman who was reading a magazine out in my waiting room that I gave this device to, and then it became quickly apparent to me he was totally illiterate. And therefore, there was this enormous barrier between myself and that patient that would not have come out.

So one of the panelists made a plea for good public education, that we just have to bring up the general education of our population, and then I think the devices will naturally fall into place.

Mr. ALEMI. As my testimony illustrated, we use phone services—you don't read anything. You're listening, and you're able to listen to a higher level than you can to read. So even if you don't have an 11th grade education or 7th grade, you're able to use our services.

In addition, I think it's important to make sure that certain modes of expression are not excluded. For example, we had a battered woman call our system, and she cried for 2 minutes on our system. I cannot see the equivalent of this anywhere on the Web or Internet. How would you show crying? What would you write? "I am crying." What does that mean?

People who are on Internet are intelligent people who have a certain level of education who have learned to express themselves in writing. It's difficult to do so. And sometimes, it's best to let people describe things spontaneously by speaking.

Mr. SHAYS. I have to get to the floor for a debate on the minimum wage. What I would like to do is have Mr. Towns close up with his last question.

But I would like to first thank all of you. And I would like to thank our court reporter, Ed Greenberg, who has helped us. Thank you very much. And I also want to thank Dave McMillen, our minority staff; and the majority staff, Larry Halloran, and Chris Allred and Tom Costa. I also want to say that after 7 years of having an employee work with me both as a case worker back in the District and in my office as a legislative assistant, and now for the subcommittee staff, Kate Hickey is leaving in a week.

One of the sad things is, when you have someone you love so much and has done so much, to say goodbye. But she's going on to a much better job in a different community. And I wish her well and thank her. She was primarily responsible for this very, very interesting hearing.

If I could give you the gavel. And also, again, if the first panel would like to make some comment at the end, we would welcome that.

Thank you, my friend.

Mr. TOWNS [presiding]. Thank you. Thank you very much.

Mr. Wasow. Yes.

Mr. WASOW. I have to remember the question for just a second. I guess I'm optimistic that the machines will get easier, more specialized, and sort of more transparent so that in many cases, you

won't even know that that sneaker you're putting on is a high performance main frame.

And so—I mean, I think what we have to recognize is that we're at a period right now where there's an enormous amount of innovation happening, and over the next years and decades, we will see that become a pervasive part of society and that these people are learning how to make that work.

Mr. TOWNS. I thank you very, very much, all of you, for your comments. And let me just say that Dr. Deering said something, and the reason I wanted to raise this—and I sort of can't leave it. I just sort of want to hear your comments on it.

I think the statement was something to this effect, that she pointed out that computer systems are capable of keeping touch of who is checking in and what information they are looking for, looking at. Do any of you keep that sort of information? And if you do, what do you do with it?

Mr. GUSTAFSON. Yes, we do in our research studies. It's with full knowledge and signed consent forms on the part of the patients, that we do this. The system does keep track of, for instance, how many times a particular instant library article is used or how many times a particular question and answer is entered into or how long people spend on the system and so on like that.

The use of that is to better understand how these systems are used and how it makes a difference in people's lives. But I think it's also extremely important that this has to be done with the full knowledge and consent of the participants.

Dr. SHELLEY. With the Health Quiz, basically, the personal information is stripped so there's no identifier, and then reports are created on large populations; for example, what percentage of our patients are diabetics versus what percentage of our patients reported past problems with anesthesia. So there is a research data base that's maintained, but without personalizing information.

Mr. ALEMI. The information that's collected in our systems is considered part of the medical record and protected the same way that the medical records are.

Mr. WASOW. We keep—the software actually collects an enormous amount of data on everywhere people go in this service. We can't track people's personal correspondence, but there is an enormous log that is created. We use that to determine how long people are spending on the service and what are the more popular areas. But we don't do anything else out of respect for the privacy of our members.

Dr. DOUMA. Pray and tell—I hope it's not too rude. Something came to mind which I think it's incredibly important in reaching the disadvantaged populations, again, whether it's economic or other reasons, in this computer business. And that is—and it's coming out of personal experience.

My mother-in-law is 75 years old and 3 years ago was taught how to go on-line. And now, she's the hub of the information resource in a retirement center. And in fact, the rate of growth of use by the elderly, in case you didn't know, is greater, a faster rate than the baby boomers. And the fastest growing club in Sun City West is the Computer Club.

In any case, we do not track—we have a twofold security system. We do not track what a screen name is doing on America Online. And the screen name is unrelated to a person's identity unless they actually choose to enter that into the system. So even though we track the screen name, we wouldn't know who they are unless they wanted to tell us. And we don't do either.

Mr. TOWNS. Let me thank all the witnesses for your testimony. I think it has been very, very informative. And, of course, before we close out, I would like to also convey to Ms. Hickey that I wish her the best in her new area. And I'm certain it will be in an area providing quality something to people, there's no doubt about that because of her commitment down through the years.

Also, to say to all of you that we look forward to working with you as we continue to look at these issues. We welcome the fact that you come to share with us, because I think that it's something that we need to get involved in right now and because as we continue to move ahead, I think that we need to move ahead in a kind of consistent fashion, recognizing that once we make a commitment, that we have to continue to move on and not to get involved in the way we have done many things in the past, where we will fund it at one point and then back off and it becomes a question as to whether this additional commitment will be there.

So we hope to have the consistencies this time. The only thing that I would like to ask all of you to do for me—and we will keep the record open for that information—if you would give me a brief kind of outline of how you think we could, from where I sit, just switch roles for a moment, as Members of Congress, that we could tie the various agencies together to make certain that the coordination and the consistency is there for the information to flow.

Am I making myself clear? Let me see—you understand the question?

OK. Fine. I would like to——

Dr. SHELLEY. I don't.

Mr. TOWNS. Let me just say, as we move forward with these kinds of things, it's important that different agencies that are supposed to do things do them in a timely fashion, that there is consistency in terms of support for these kinds of things.

Dr. SHELLEY. Sure.

Mr. TOWNS. Members of Congress we feel have a role in that, because we are responsible for communicating with everybody, supposed to, anyway. So we want you to give us some ideas and suggestions as to how we might do that.

In other words, I want you to become a Member of Congress for a few days and just give us this information so we can look at it as we continue to move on. I know you probably have a lot of other ideas and suggestions that you would like to make to us, but time will not allow it.

So what we're saying is that this would be an opportunity for us to keep the record open for a number of days for you to give us that information. So thank you again for your testimony. You have been extremely helpful. Thank you very, very much. This hearing is now adjourned.

[Whereupon, at 12:40 p.m., the subcommittee was adjourned.]