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# CONSUMER HEALTH INFORMATICS

## Emerging Issues

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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.<sup>1</sup>

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## 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 to 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 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.<sup>2</sup>

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

<sup>2</sup>Council on Competitiveness, Highway to Health: Transforming U.S. Health Care in the Information Age, March 1996, p. 29.

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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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## 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,

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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

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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.

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## 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

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- *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.

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## 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

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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,<sup>3</sup> and at least 6 percent lack telephones.<sup>4</sup> 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<sup>5</sup> 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 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

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<sup>3</sup>Council on Competitiveness, *Highway to Health*, p. 34.

<sup>4</sup>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.

<sup>5</sup>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.



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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

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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.

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## 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

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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.

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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.

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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.

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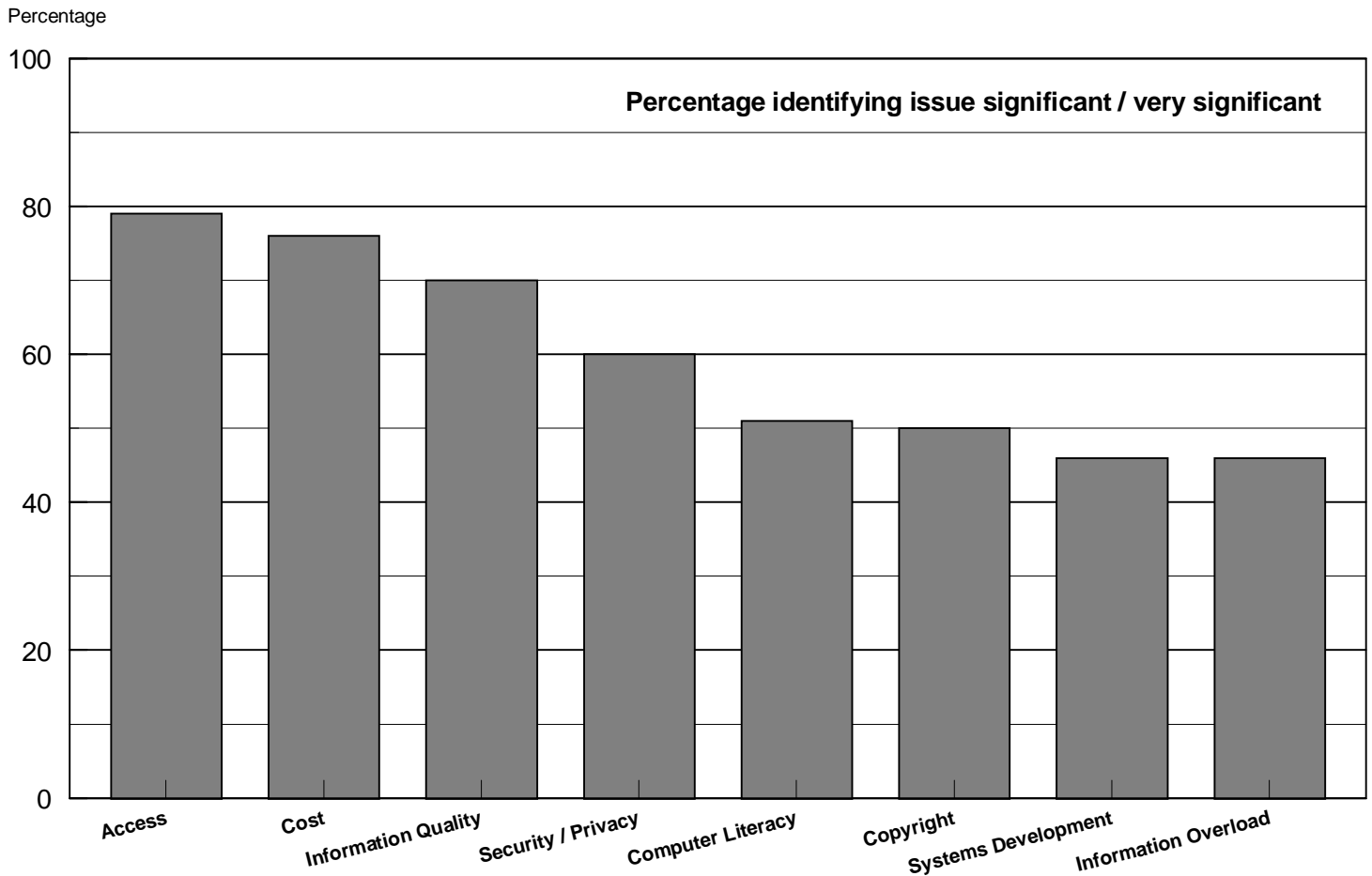
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# Sample of Informatics Projects by Location, Description, Target Users, and Technology Employed

<b>Project/location</b>	<b>Description</b>	<b>Target users</b>	<b>Technology</b>
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.

# Experts' Views on Relative Significance of Consumer Informatics Issues



Source: GAO analysis of 80 experts' views.

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# Sample of Federal Government Agencies Involved in Consumer Health Informatics

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**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

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