Subcommittee on Science Technology and Space of the Senate Committee on Commerce, Science, and Transportation

Hearing on E-Health and Technology: Empowering Consumers in a Simpler, More Cost-Effective Health Care System

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Good afternoon. I want to thank Chairman Wyden, Ranking Member Allen, and the members of the Subcommittee for the opportunity to be here today. Improving the quality and cost-effectiveness of health care for our Nation's more than 270 million citizens is one of the great challenges of our time, so I am pleased to be able to join in this discussion.

Background

I am here as a representative of the President's Information Technology Advisory Committee, or PITAC, and the co-chair of PITAC's Panel on Transforming Health Care. The PITAC is a group of 22 information technology leaders in industry, research, and academe whose charge is to provide independent guidance to the President on maintaining U.S. leadership in high performance computing, networking, and information technology research and development. In February 1999, PITAC issued "Information Technology Research: Investing in Our Future," a major report on the status of information technology research and development. In that report, we described 10 major areas of our national life – including health care – in which information technology could have a transforming impact that will benefit all Americans.

As a followup to that initial report, PITAC established a number of Committee panels to conduct more targeted analyses of the information technology barriers and opportunities in specific transformational challenge areas. To date, PITAC has issued panel reports on "Transforming Access to Government Through Information

Technology" ((September 2000); "Developing Open Source Software To Advance High End Computing" (October 2000); and "Digital Libraries: Universal Access to Human Knowledge"; "Using Information Technology To Transform the Way We Learn"; and "Transforming Health Care Through Information Technology" (all in February 2001). My co-chair on PITAC's Panel on Transforming Health Care was Dr. Ted Shortliffe, professor and chair of the Department of Medical Informatics at the College of Physicians and Surgeons, Columbia University, who has been particularly interested for several years in the Federal role in health care information technology. The Panel reviewed the current literature and consulted widely with Federal and private-sector experts over the course of a year in developing the findings and recommendations of our report.

PITAC Transforming Health Care Report

Our panel concluded that information technology offers the potential to expand access to health care significantly, to improve its quality, to reduce its costs, and to transform the conduct of biomedical research. The quality of U.S. health care and medical research are the envy of the world, but U.S. health care costs as a percentage of gross domestic product are among the highest in the world and are increasing despite recent changes in health care organization and financing. Further, a recent report from the Institute of Medicine (IOM), "To Err is Human," points out that despite our favorable reputation for especially complex care management, our health care system is not nearly as safe as it could be. The report argues that significant improvements in care would be possible if modern clinical information systems were widely implemented and a sound national health information infrastructure were in place.

Because the focus of this hearing is how information technology can empower health care consumers, I want to read you part of our Panel's patient- and consumer-centric vision of better health care enabled by information technology:

"Telemedicine applications are commonplace. Specialists use videoconferencing and telesensing methods to interview and even to examine patients who may be hundreds of miles away. … Patients are empowered in making decisions about their own care through new models of interaction with their physicians and ever-increasing access to biomedical information via digital medical libraries and the Internet. New communications and monitoring technologies support treatment of patients comfortably from their own homes."

The health sector will experience unprecedented change as it begins to take advantage of information technologies to increase productivity and to improve the quality of care in the ways the PITAC panel envisions. While new technologies can provide great opportunities for advances, key challenges exist to realizing the potential benefits to Americans' health and health care. The Panel made the following findings about these challenges:

1. The U.S. lacks a broadly disseminated and accepted national vision for

information technology in health care.

Health care organizations are not well prepared to adopt information technology and applications effectively. Health care is largely a decentralized industry populated by diverse organizations with different motives, resources, and incentives. Fiscal constraints hinder the industry's ability to make major investments in information infrastructure and applications unless these investments can be shown to lead to significant and low-risk returns. Provider organizations lack information about the efficiency of information technology solutions in terms of both cost and quality, making it difficult for them to make decisions about information technology investments. We now have sufficient evidence to state that computer-based patient records can substantially improve patient care, outcomes, and costs. Yet to date we do not have the national commitment to assure that Americans will reap the benefits of this technology.

2. Critical, long-term research, technology, and policy issues need to be addressed if we are to realize the potential of information technology to improve the practice of health care.

While significant advances in information technology have been achieved, many hard problems remain. For example, user interfaces that are easier to use and more easily integrated into the ergonomic patterns of health care can catalyze greater acceptance and use of innovative computer-based tools in medicine. Robotics and remote visualization methods supported by high-reliability and low-latency communications are needed to enable applications such as telepresence surgery. Reliability of systems and software is critical for many health care applications. Human life may be at risk if information sent to medical monitoring or dosage equipment is corrupted or degraded, or if electronic medical records cannot be accessed in a timely, reliable way.

Knowledge repositories are also an important research topic, including techniques for integrating data from multiple sources. Stronger forms of authentication are needed, both for persons accessing data and for assuring the integrity of the information. Methods are needed to protect patients' privacy while allowing valuable medical research and necessary reimbursement tasks to be performed. Better access-control methods would make it possible to partition and isolate the data elements as needed to protect patient privacy. Improvements in computational capability are therefore essential, including faster processing and more networked resources to meet the increased demands of modeling complex systems and performing information retrieval, data analysis, and automated inferencing.

From a policy perspective, perhaps the most significant problem is the lack of reimbursement for a range of applications that have demonstrated value, e.g., telemedicine, patient-provider interactions over the Internet, efforts to reduce medical errors, and initiatives that link a patient's data across provider organizations. We have sufficient evidence, for example, that computer-based patient records can substantially improve patient care, outcomes, and costs. But many provider organizations lack

information about the efficiency of IT solutions in terms of both cost and quality, so it is difficult for them to make appropriate decisions about IT investments. (For a history and discussion of the health care community's role in networking, see Edward H. Shortliffe's article "Networking Health: Learning From Others, Taking the Lead," Health Affairs, November/December 2000, attached to this testimony.)

Further complicating matters is the fact that health care providers are currently licensed by individual states and are generally prohibited from providing care across state lines. This becomes a clear issue when a patient is in one state but the physician at the other end of a telemedicine link is in another. Liability claims are also handled at the state level, with considerable variation among states.

3. The introduction of integrated decision-support systems that can proactively foster best practices requires enhanced information technology methods and tools.

Decision-support tools can provide critical links between a current patient's condition and previous clinical studies. Existing systems largely focus on detecting errors at the source, through such methods as range checking, alerts, and reminders, or post-hoc quality monitoring and review. While these types of systems are vital components for improving quality of care, important information is often unavailable or inaccessible because it is spread across multiple information systems and/or organizations with differing systems. This can result in poor coordination of care and increased illness and mortality.

Scientists are generating enormous amounts of raw data from clinical trials as well as bench research. However, making sense of the raw data in the context of previously published research requires sophisticated information retrieval and management approaches not yet invented. For example, the recent death of a healthy volunteer in an asthma clinical trial can be traced to inadequate review of the historical literature regarding known, fatal reactions to a drug. In spite of the impressive National Library of Medicine databases, vital information is still not "at our fingertips." (See July 17, 2001, article from The Baltimore Sun attached to this testimony.)

Two examples of other technologies that could make a difference in patient care: automated reminders to clinicians and patients regarding treatments, followup visits, and the like; and Rapid Alerts to clinicians and patients regarding abnormal lab findings. However, software that will deliver the power and functionality required for such time-critical communications is lacking in most hospitals today.

As a new report from the Robert Wood Johnson Foundation points out, "eHealth interventions have been shown to enhance social support and cognitive functioning; enhance learning efficiency; improve clinical decision-making and practice; reduce health services utilization; and lower health care costs among certain groups." However, the report goes on to note that "most assessments of eHealth interventions

have been limited to small groups that may not be representative of the parent population, have not been randomized control trials, had limited follow-up periods or only assessed proprietary interventions that may or may not be replicable.... eHealth developers do not routinely conduct evaluations, especially post-market assessment for effectiveness. And when commercial companies and other private sector organizations DO conduct evaluations, the results are often not publicly available." (See Eng, T.R., "The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care," The Robert Wood Johnson Foundation, 2001. Available at: www.rwjf.org.)

We cannot wait for industry to deliver solutions because we do not yet know all of the questions. What we need is a national commitment to do the research it will take to develop an array of 21st century patient-centric applications of information technology. The challenge of going beyond current methods to ones that proactively foster best practices will require a whole new generation of advanced technologies based on efforts in the following areas:

- Expanding the range and granularity of routinely captured data
- Standardizing terminology
- Developing robust techniques for incorporating new data types into existing clinical data repositories, e.g., images and patient genotype
- Organizing and collecting large-scale databases to determine best practices
- Developing guidelines based on such evidence
- Implementing guidelines so that they are usable effectively at the point of care, including embedded decision support that is continually updated as new evidence accumulates
- Reducing the cost and difficulty of integrating applications that reside on heterogeneous technologies

4. Achieving the potential of information technology to improve health care will be constrained until we develop a larger cadre of researchers and practitioners who operate at the nexus of health and computing/ communications.

In part, the missing national vision of information technology's key role in the U.S. health care system is due to a lack of critical investment by the biomedical community in computer infrastructure and enabling technologies. This issue becomes increasingly difficult to solve because the number of individuals who understand both the health care milieu and information technology is remarkably small. Yet, if we are to improve health care quality, increasing the number of trained professionals with biomedical information technology expertise is a critical need.

5. The biomedical community, including the Federal research agencies, has tended to rely on information technology innovations that are produced by investments in other parts of Government.

Although the quality of U.S. health care is increasingly dependent on the effective use of new and emerging information technologies, Federal health agencies have played a limited role in supporting research and development in computer science. Unfortunately, the health care and biomedical research communities have generally viewed information technology as a tool to enable health care applications and support biomedical research, rather than a critical research field. The Department of Health and Human Services (DHHS) has heavily leveraged information technology research and development investments made by other Federal agencies such as the Defense Advanced Research Projects Agency (DARPA), the Department of Energy (DOE), the National Aeronautics and Space Administration (NASA), and the National Science Foundation (NSF). While DARPA, DOE, NASA, NSF, and other Federal agencies consistently make significant investments in fundamental information technology research and development, their primary mission is not health care and therefore their priorities do not necessarily match the critical needs of health care research and education.

DHHS has failed to make vital investments in fundamental information technology research and development and, as a result, health care lags behind other sectors. If DHHS does not begin to make substantial investments in information technology research and development, two serious problems will arise. First, the pace at which biomedicine benefits from information technology research will be adversely affected. Second, the needs of the biomedical community will not be reflected in the priorities of the other Federal agencies unless the biomedical community itself is involved in information technology research. Similarly, the biomedical research agencies must collaborate on an equal footing with the other Federal research agencies that have dominated information technology research in the past.

6. The role and management of information technology in the Department of Health and Human Services has several limitations, which must be addressed if the health care community is to benefit from the promise of the information age.

DHHS does not have a clear, strategic vision of the benefit that the department and all of its agencies could receive from information technology research and use of information technology tools. It is evident that the decentralized management approach of DHHS has adversely affected both the development of a coherent information technology vision and the influence of departmental activities regarding information technology and its role in health care and biomedical research. It is important to change this practice and ensure that DHHS has the necessary leadership and budget and a coordinated information technology effort across all its agencies. In our discussions with DHHS agencies, it became clear that they do not have a mandate or budget to support information technology research, even though it is fundamental to their mission.

Although the Administration and Congress have placed a high level of confidence in information technology's benefit to this country, DHHS is not perceived as a significant player in Federal information technology research or policy development. It is clear,

however, that state-of-the-art research advances in any field require state-of-the-art investments aimed at solving problems, developing the technology, and building the right infrastructure.

PITAC's Recommendations

Over all, our report argues that the Nation must invest in research and development focused on realizing the potential of information technology to support 21st century patient-centered health care, just as we are focusing on the potential of research findings in microbiology to help treat and cure human diseases. We believe that we cannot get where we need to go within the current patchwork, piecemeal implementations of technologies, most of which were not designed for the life-and-death issues of patient care or the scale and demands of health information systems.

1. The Federal government should establish pilot projects, Enabling Technology centers, and large-scale research programs to extend practical uses of information technology to patient care, health care systems, and biomedical research.

The Enabling Technology centers could build on the very good program models of the National Library of Medicine's integrated academic systems and telemedicine grant programs, which have supported the development of applications linking distributed organizations via networks and prototyping technologies for specific health care uses. (For examples of NLM advanced networking applications projects, see list attached to this testimony.) These centers would serve as a resource for developing the dual-trained workforce in biomedical information technologies that we believe is critical for the future, and would also bring together researchers, clinicians, patients, providers, industry, and government stakeholders to solve health care-specific problems.

With regard to large-scale research projects, the Nation is making significant investments in disease-oriented studies. But there is very little funding to support large scale, long-term studies of information technology interventions with large populations – across disease types. DHHS's Agency for Healthcare Research Quality and the National Library of Medicine of the National Institutes of Health have funded most of the health IT research to date. And NLM has also led in building medicine's vital resource databases, including the PubMED and genome databases. However, the funding is inadequate to meet the depth and breadth of the problems. For example:

Use of provider/patient email – Is it clinically effective? Cost effective? Does it reduce patient visits? Improve patient satisfaction?

Telemedicine for consultations – Studies have repeatedly shown high levels of satisfaction with this approach among rural patients, their primary care providers and specialists. In spite of this apparently positive response, the approach not yet in general use. Many limiting factors have been identified, including cost of rural connectivity and regulatory issues. However, adequate research funding of studies over longer periods of time could provide the answers needed to solve these problems.

Remote-care applications that integrate sensor technologies and/or remote instrumentation to monitor patients – For example, a significant number of people who reside in nursing homes are there more for health "security" reasons than for heath care "needs." Many residents in extended-care facilities could be cared for at home at significantly reduced costs if the appropriate telemedicine tools were available to enable remote monitoring. Additionally, many of the home-health visits conducted today are based on the need to observe or monitor a patient's status, a function that could be accomplished through interactive video systems coupled with the appropriate instrumentation and a simple-to-use interface.

Using the Web to obtain health information – Increasingly, patients (and providers) seek medical information on the Web. But they encounter a bewildering quantity of information of variable quality. We need to study the types of questions patients are seeking answers to and where are they looking, and develop strategies for helping them find answers. A particular problem based on my own work with Native American tribes is that much of the available health information on the Web does not adequately address the needs of minority populations. (See "Health Information on the Internet: Accessibility, Quality, and Readability in English and Spanish," Berland, JAMA, Volume 285(20), 23/30 May 2001. This empirical study found issues in both health content and search engine efficiency.)

Federal Leadership

The following recommendations of PITAC's report flow from the Health Care Panel's view that the Federal government's key health-care agency, DHHS, must develop a much more active and visible leadership role in articulating, developing, and modeling information technology methods and systems for improving U.S. health care. We also urge that NIH and other Federal science agencies collaborate on an advanced infrastructure for the biomedical research community. And we ask the Congress to enhance existing rules on information privacy. These proposals are needed to spearhead the broad changes we are describing across the decentralized and diversified landscape of the Nation's health care sector.

2. NIH, in close collaboration with NSF, DARPA, and DOE, should design and deploy a scalable national computing and information infrastructure to support the biomedical research community. This infrastructure should include an aggressive biomedical computing capability similar to that of the Department of Energy National Nuclear Security Administration's (DOE/NNSA) Accelerated Strategic Computing program.

Computational biology and other biomedical problems require the fastest computing cycles and information processing capabilities achievable today. And as we seek to improve our knowledge of the human body, these computing requirements will grow exponentially. There should be a biomedical equivalent of the DOE/NNSA program to provide multi-teraops/teraflops computing capability to high-end users and to fund the development of improved algorithms and enabling technologies for terascale systems.

Facilities with mid-level computers also should be made available for researchers to develop and test software before moving to large systems. These mid-level systems can also be used for developing new algorithms and applications for biological problems.

To enable this distributed, scalable computing environment, investments are needed in software to support grid technologies to permit dynamic allocation of computing and information processing capability across geographically distributed locations as needed. Long-term information storage and management of biomedical databases are also important computing infrastructure requirements. DHHS should work with the community to decide which databases are to be maintained, for how long, and by whom. DHHS also should provide the necessary funding to support the infrastructure needed to maintain the databases over the long term.

3. Congress should enhance existing privacy rules by enacting legislation that assures sound practices for managing personally identifiable health information of any kind.

Protections are needed that deal with unauthorized access and disclosure and that allow for appropriate access and amendment by patients. Governing the stewardship of and access to medical information is an important issue. Legislation should identify the national standards by which information can be shared, should permit electronic authentication of information, and should include sanctions/penalties for violations. Despite the recent announcement of privacy regulations in response to the Health Insurance Portability and Accountability Act of 1996 (HIPAA), uncertainties can be dealt with convincingly only by a clear legislative mandate.

4. Establish programs to increase the pool of biomedical research and health care professionals with training at the intersection of health and information technology.

The Panel applauds the efforts of the NIH 's Biomedical Information Science and Technology Initiative to establish National Programs of Excellence in Biomedical Computing to support learning at the interfaces among biology, mathematics, and computation. Such programs can play a significant role in educating biomedical-computation researchers. DHHS should identify and nurture similar programs to provide training at the intersection of information technology and health care professionals. For new applications of information technology to health care to be envisioned, developed, and implemented, it will be necessary to build teams of health care application experts, biomedical researchers, and computer scientists. Such teams can build bridges among near-, mid-, and long-term R&D to help ensure rapid adoption of new technologies in the health care system. DHHS should explore other educational opportunities, such as expanding health informatics training programs and curricula within the schools of health professions and computer science departments.

5. DHHS should outline its vision for using information technology to improve health care in this country and subsequently devote the necessary resources

to do the basic information technology research critical to accomplishing these goals in the long term.

DHHS should develop an agenda to remove the policy barriers that currently inhibit the use of information technology in support of health care. This might, for example, include the development of an expanded agenda at the centers for Medicare and Medicaid Services (CMS) (formerly the Health Care Financing Administration) to evaluate the impact of such technologies on care quality and costs and to provide reimbursement (or other incentives) should the impact prove to be socially valuable.

The Department should also establish an aggressive research program in computer science that is motivated by health needs. It is important that the research program address long-term needs, rather than the application of existing information technology to biomedical problems. Some entities within DHHS, most notably NLM but also other elements of NIH and AHRQ, have invested in research in applications of computing and communications technologies. But much of this work has had short-term goals and DHHS itself has not made information technology research and development in health-related activities a priority. Financially stressed health care organizations will not increase their commitment to the use of information technology without strong leadership and demonstrations of value. (For examples of the types of research and development DHHS might encourage, see pages 14-15 of "Transforming Health Care Through Information Technology.")

6. DHHS should appoint a senior information technology leader to provide strategic leadership across DHHS and focus on the importance of information technology in addressing pressing problems in health care.

Information technology is of critical importance to the Nation and can be instrumental in providing the best possible health care to all of our citizens. At this time, information technology research and use are not viewed within DHHS as strategically as is necessary. We therefore recommend that DHHS create a high-level position designed to provide the necessary vision for the agency in its efforts to incorporate information technology in its agency mission and strategy. While we cannot best judge how this should be accomplished, we recommend that the position be at least at a level equivalent to the deputy undersecretary. This person should be an expert who operates at the nexus of health and computing/ communications. In addition, a budget should be provided to facilitate this person's coordinating and educational activities.

Conclusion

PITAC strongly believes that information technologies hold the potential to dramatically improve the U.S. health care system. The barriers are diverse, ranging as they do from basic technology questions that require fundamental research, to human, organizational, and social factors that complicate the application of technology in a complex setting such as health care. But in almost all such areas, there is a role for the Federal government to play. Our health care report has outlined those roles and we hope that you and your colleagues will find our suggestions engaging and persuasive.

The Nation has much to gain if IT is more effectively applied to prevent disease, to reduce errors and expense, and to improve the overall quality of health care for our citizens.

The PITAC will be happy to provide the subcommittee with additional information and to work with members pursuing these significant aspects of U.S. health care quality.

Thank you.