Information technologies are transforming the way health care is delivered. Innovations such as computer-based patient records, hospital information systems, computer-based decision support tools, community health information networks, telemedicine, and new ways of distributing health information to consumers are beginning to affect the cost, quality, and accessibility of health care. The technologies that support these applications—relational databases, network communications, distributed processing architectures, optical disk storage, and others—are used today by some health care providers and payers. Yet information technology is often found in isolated “islands of automation” in health care provider and payer institutions. Despite the incorporation of high technology into almost every other aspect of clinical practice, information technologies have not been fully embraced.

Meanwhile, transformations in the way health care is delivered are creating new opportunities for innovative applications of information technologies. The health care delivery system is currently undergoing many changes, including the emergence of managed health care and integrated delivery systems that are breaking down the organizational barriers that have stood between care providers, insurers, medical researchers, and public health professionals. These barriers have supported a clear demarcation between clinical health information and administrative health information and reinforced a long-standing distinction between treatment of disease and preservation of health. These distinctions are gradually eroding as new health care delivery patterns emerge that are supported by, and in some cases reliant on, the widespread use of networked computers and telecommunications.
This report discusses the synergy between information technologies and new trends in the health care delivery system as health care is brought online. It identifies some of the opportunities to improve health care delivery through increased use of information technology, and discusses some of the conceptual, organizational, and technical barriers that have made its adoption so uneven. The report identifies key technologies and shows how they are being used to communicate clinical information, simplify administration of health care delivery, assess the quality of health care, inform the decisionmaking of providers and administrators, and support delivery of health care at a distance.

CHALLENGES AND OPPORTUNITIES FOR INFORMATION TECHNOLOGIES

The technologies used for collecting, distilling, storing, protecting, and communicating data are widely used throughout American industry. In the health care industry, however, their application has been limited to scattered islands of automation, usually limited to discrete departments within hospitals. Computers are widely deployed, but not widely connected. Clinical and administrative health information are rarely commingled. Both types of health information are still stored and conveyed primarily in paper form. Health information is rarely converted to digital form and shared among the clinics and primary care offices where most health care occurs, the hospitals and critical care units where most health care dollars are spent, or the population-based health services that address community-wide health issues. Computers are typically used to organize and administer specific, limited types of health information, but are not linked into an infrastructure that might allow broader efficiencies or higher quality health care.

Figure 1-1 shows the level of adoption of some selected information technology applications as reported by chief information officers (CIOs) of primarily large health care institutions. As the figure indicates, almost 70 percent of those responding have introduced electronic systems for submitting insurance claims, and more are in the process of adopting them. Technologies that allow communication between computers at disparate locations, for example physician-hospital data networks or enterprise-wide networks, are being adopted or planned by a substantial number of these institutions as well. Computer-based patient record (CPR) systems, which are difficult to implement because they require such close integration between many different systems, are at least in the planning process, according to 50 percent of responding CIOs, but so far only about 20 percent consider that they have CPRs operating at least at an experimental level. When asked which technologies they were currently evaluating conceptually for future implementation, the two most frequently mentioned by CIOs were community health information networks and telemedicine.1

The health care delivery system has several unique characteristics that discourage the spread of information technologies. Health professionals perform a wide variety of tasks including rapidly changing combinations of “hands-on” care, inductive and diagnostic thinking, detailed record-keeping, patient education, and communication with colleagues. Most of the hardware and software approaches that address one of these aspects of medical practice intrude unacceptably on some other aspect: computers are not yet as useful, ubiquitous, and handy as the stethoscope and other common medical technologies. In addition, medical practice is extraordinarily complex and it changes rapidly. Systematizing even the process of performing medical procedures, much less rationalizing the language and scientific knowledge underlying those procedures, is an almost intractable problem. Despite the ongoing efforts of standards-setting bodies, no unified conceptual model exists that is powerful enough to construct the mapping between the information that must be

stored in computer databases and medicine as it is practiced. In a sense, there is not yet a consensus about what information should be kept in computer-based patient records or how it should be described, organized, and indexed.

Apart from the complexity of clinical knowledge and practice, there are structural reasons that discourage implementation of information technologies in health care settings. In addition, many communities have only a few hospitals or major insurers. The cooperation necessary to interconnect medical information within a horizontal layer of the health care system may be seen as anticompetitive and subject to antitrust regulation, or it may be hindered by organizations that regard their internal information systems as competitive advantages and accumulated patient records as corporate assets.

Information technologies tend to flatten organizations and may not mesh well with the rigidly defined job roles and hierarchical structure of current medical practice (see box 1-1). Many types of organizational changes will emerge throughout the health care system if information technologies are widely adopted. In other industries, changes associated with the introduction of information technologies have included large reductions in the demand for some types of workers (e.g., mid-level managers and bank tellers), increased responsibilities for workers in jobs that traditionally involved little decisionmaking (line workers in manufacturing industries), and an increase in
competition for local experts from nonlocal sources (discount stockbrokers, for instance). Similar changes are likely to occur for health professionals, along with a redistribution of status, responsibilities, and remuneration associated with the various health disciplines.

Information technologies not only redefine jobs, but they may have more subtle ramifications as well. The widespread adoption of integrated information systems will challenge the legal system. Information technologies facilitate alliances between geographically separate parties. Thus, they may challenge the existing structure of state medical licensing and malpractice laws, as well as “pen and quill” laws that require paper-based medical recordkeeping. Consolidations and mergers among the many companies offering managed health care reflect the ability of computer networks and digital telecommunications to act as a nervous system that can connect previously independent parts of the health care delivery and administrative systems, forming new bodies known as integrated delivery systems. These new corporate structures may pose antitrust questions as they challenge traditional providers of health care in isolated markets.

Information technologies diffuse decisionmaking and responsibility because they are developed, maintained, and employed by a variety of people. Physicians—who have held unique positions of status and compensation, as well as legal responsibility and risk, under the traditional systems of licensure and malpractice law—may be put in the uncomfortable position of being solely responsi-
Information technology also can change job roles. For example, when physicians place medication orders at a computer terminal, they take on a data entry task that might previously have been done by a ward clerk, a pharmacist, or a pharmacy clerk. With proper design, the technology can help integrate this task with others the physician performs—retrieving information about the patient’s condition, looking up the proper dosage and use of medications, or making judgments and decisions about additional tests and treatments. Whether data entry is an additional burden, or an integral part of an improved and more efficient process for rendering care, depends on a wide variety of personal, institutional, hardware, software, and interface design factors.

In some cases, role changes are induced by other organizational changes in which information technology is a facilitator. For example, one way that health care organizations are reducing costs is by redesigning work so that tasks once done by high-cost personnel are now done by lower cost personnel. For example, much primary health care previously done by physicians is now being done by physicians extenders like physician assistants and nurse practitioners. In some hospitals, work previously done by licensed and registered nurses is now done by nursing aides—sometimes labeled patient care technicians, while nurses take on the role of managing a team of caregivers. This trend is typical of a “reengineering” movement in hospital management known as patient-centered care or patient-focused care—as opposed to department-focused care. Computer technologies—including computer-based decision support tools and treatment protocols, online patient information systems, patient monitoring devices, and teleconferencing systems—can support and assist people giving care in these new ways.


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TRENDS IN THE HEALTH CARE SYSTEM

Aggressive Cost Management

A major concern for providers, payers, policymakers, and consumers alike is the rising costs of delivering care. Health care expenditures increased from 5.9 percent of gross domestic product in 1965 to 13.9 percent in 1993. Total expenditures for health care in 1993 were $884.2 billion. Government sources pay for about 43 per-

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cent of this total; the federal government alone pays nearly 32 percent. Health care is also a major segment of the economy, employing approximately 10 million people, about 2.6 million of whom do primarily administrative work.³

As the costs of health care have continued to rise, there have been concerns in government and in the industry itself about how to contain and reverse the increase. In the 1990s, particularly in the 103d Congress, a number of proposals were made for far-reaching reforms in the health care industry. At the same time, within the health care and insurance industries, many initiatives to control costs are already under way. In fact, perhaps due in part to these efforts, the growth rate of health care costs appears to have slowed during the 1990-93 period.

One of the major influences in the health care industry has been the growth of managed health care. “Managed care” is a somewhat nebulous term, but generally refers to a “system of managing and financing health care delivery to ensure that services provided to managed care plan members are necessary, efficiently provided, and appropriately priced.”⁴ Managed care organizations use a number of techniques to control access to providers, contain costs, manage utilization of resources, and ensure favorable outcomes for patients.

The number of people enrolled in managed care plans has increased dramatically in the past 20 years. By 1992, enrollment had grown to over half of all employees covered by employer group health insurance.⁵ As shown in box 1-2, the concept of managed care has expanded to include many types of health plans and delivery systems. Many traditional fee-for-service health insurance plans (those that reimburse members for health care payments) are also using at least some care management techniques to manage their costs.

### Integration of Health Services

Health care has historically been a very fragmented industry. Routine medical care, crisis medical care, medical insurance, medical research, and management of public health typically have been handled by entirely separate organizations in business, government, and universities, and a large number of intermediary institutions as well. There are more than 1.2 million health care providers—ranging from solo practitioners to 1,000-bed hospitals—and they are often isolated in separate corporate entities from the more than 3,000 private insurance payers that distribute payments for health care services. The providers and insurance companies are further isolated from the medical research community, government health care agencies, and public health organizations. A network of private-sector intermediaries has formed to facilitate the complicated relationships between the various organizations. It is unlikely that any of these entities will be willing to collect or organize data that save money or effort for some other organization, but deliver the intermediary no immediate benefit; systemic savings may be irrelevant in a vertically fractured industry.

Some of this fragmentation may be reduced with the current trend toward vertical and horizontal integration of providers and payers into systems that offer the full “continuum of care” to covered populations. An integrated delivery system is one that brings together hospitals, primary care providers, nursing homes, home health care providers, pharmacies, and other services into a single system through purchase, merger, joint venture, contract, or other means. As hospital ad-

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BOX 1-2: Managed Care

Managed care can refer to both the elements of managing care and the institutional structures within which care is managed. To some, managed care means the use of management tools such as preadmission certification (for ensuring that only members who need hospital care are admitted to the hospital), concurrent review (ensuring that necessary and appropriate care is delivered during a hospitalization), or financial incentives or penalties for both providers and plan members. To others the term is equated with alternative delivery systems that are variously known by names such as health maintenance organization (HMO) or preferred provider organization (PPO).

In contrast to traditional fee-for-service or indemnity insurance plans where the insurer simply reimburses the insured individual for incurred health expenses and has no direct relationship with the providers of care, managed care organizations create a direct relationship between the insurer and the provider of care. Whether physicians are salaried employees or contractors, they have a relationship with the managed care plan wherein they give up some clinical and financial autonomy to that organization. The consumer who joins a managed care plan also surrenders some freedom of choice. The HMO or PPO in turn takes on a managerial role with the hope of containing costs and enhancing the quality of care.

One concept used in certain forms of managed care is capitation. Under capitated payment systems, providers receive a set payment per patient per period, regardless of the amount of services they provide. Providers who exceed their budgets will suffer losses. A second concept common to managed care is the limitation on the patients’ choice of providers. Some plans only allow patients to choose from a panel of providers associated with the plan (“closed panel”). Others permit patients greater flexibility, but require patients to pay a higher share of costs when using outside providers. While the concepts of capitation and limitations on the patient’s choice originated with early HMOs, they are now pervading the whole health care industry, and many insurance plans, including traditional indemnity plans, may include these features to some degree. Some managed care organizations have tighter controls—both over payments and over patient-provider relationships; others maintain looser controls. Closed-panel HMOs are generally the most restrictive, while independent practice associations (IPAs)—HMOs where physicians work under nonexclusive contracts and may also have fee-for-service patients—are less so, as are PPOs.

Managed Care and Cost Savings

According to recent studies, care management techniques reduce health care costs, primarily through the reduced use of services. For example, the Congressional Budget Office (CBO) reports that, compared to indemnity plans, closed-panel HMOs reduce the use of medical services by about 19.6 percent and IPAs reduce use by about 0.8 percent. The combined average effect of all HMOs is a reduction in services of 7.8 percent when compared with the current mix of indemnity plans.\(^1\) Less restrictive types of managed care have not shown such significant reductions, according to CBO.


\(^1\)U.S. Congress, Congressional Budget Office, The Effects of Managed Care and Managed Competition (Washington, DC: Congressional Budget Office, 1995).
missions and inpatient days have declined because of cost control efforts begun in the 1980s, many hospitals have entered these other lines of business. Some integrated delivery systems are being organized by insurers or managed care organizations.

Increasing Value of Digital Information

New patterns in health care delivery are enhancing the value of clinical health data and creating incentives for collecting and disseminating health information electronically within and between organizations. As managed care organizations grow and fee-for-service care wanes, doctors and other practitioners have both a financial interest in delivering low-cost care and incentives for documenting and analyzing their care practices. Administrators in Health Maintenance Organizations (HMOs) and integrated delivery systems have long sought to reduce transaction costs (after an initial investment in equipment and software) by computerizing internal communications and automating communications with suppliers and other business partners. In addition, they have a vested interest in understanding the clinical details of how care is delivered in order to efficiently manage resources.

For example, it is possible to use administrative records alone to limit overuse of optometry services by approving eye examinations purely on the basis of elapsed time since the last exam. However, care can be more prudently and perhaps compassionately managed by considering not only the time of the last billing, but also the clinical record of that visit and other health information about the patient. Were the previous results normal, or did they indicate a problem? Does the patient have any other conditions that might warrant frequent eye examinations? Could the current complaint be due to an adverse reaction to a prescribed medication and, hence, warrant a visit to the prescribing physician rather than an optometrist? This fine-grained analysis of clinical records is contingent on standardization and digitization of clinical records because paper records are generally inadequate for these purposes.

Finally, the government has a stake in helping to develop inexpensive, standardized approaches to information exchange so it can effectively fund medical research, manage widespread public health problems, reduce its administrative costs, and reduce the cost of the health care it purchases and provides through Medicare, Medicaid, veterans’ care, and employee insurance programs. An indication of the magnitude of this interest is the designation of health care applications as a key component of the National Information Infrastructure (NII) by the Administration’s Information Infrastructure Task Force (IITF). Appointed by the President, the IITF is comprised of high level representatives of the federal agencies that play a role in developing and applying information and telecommunications technologies. The IITF’s Committee on Applications and Technology coordinates efforts to develop, demonstrate, and promote applications of the NII and develops and recommends technology strategy and policy to accelerate its implementation. One part of this committee is the Health Information and Applications Working Group. This group is again divided into subgroups in the categories of telemedicine, consumer health information, standards, and emergency medicine.

These private and governmental interests in digitizing health information in order to manage costs and integrate delivery of health services are manifest in a slow but perceptible trend toward standardization of health care information and optimization of care delivery. These processes are occurring on many levels. The medical and computing communities are slowly developing: a) lexicons for consistently describing medical care, b) consensus standards for exchanging medical data between computers, and c) models for how to collect and organize medical information digitally. Protocols for standardizing delivery of care and metrics for measuring the quality of health care services are being developed, as well as decision support systems that may increase the efficacy of medical decisions. And throughout the health care delivery system, innovative applications of in-
formation technologies are being studied, tested, and implemented.

CONGRESSIONAL INTEREST

Recognizing the changes occurring in both health care and telecommunication technology and their relevance to the congressional agenda, the Chairman of the Senate Committee on Labor and Human Resources asked the Office of Technology Assessment (OTA) to conduct a study on the impacts of information technology on the health care system. The request was supported by the Chairman of the House Committee on Energy and Commerce.6

Recently, there have been numerous legislative initiatives addressing aspects of incorporating information technologies into the delivery of health care. In the 103d Congress, several comprehensive health care reform bills were introduced,7 and this pattern has continued in the 104th Congress. These bills seek to restructure various aspects of the payment and insurance framework of the health care industry, but, in addition, they often specify procedures for simplifying administration of health care delivery through the use of information technologies. For example, several recent bills direct the Secretary of the Department of Health and Human Services (DHHS) to adopt uniform standards for various medical data, based on the work of standards committees accredited by the American National Standards Institute and on the advice of groups such as the Workgroup for Electronic Data Interchange and the Computer-Based Patient Records Institute.8

The bills call for standards for:
1. defining common sets of data elements to be stored electronically in patient records,
2. performing administrative transactions,
3. assigning uniform patient and provider identification numbers,
4. assigning codes to medical procedures and descriptions,
5. applying electronic signatures, and
6. ensuring patient privacy and data security.

Most bills specify the adoption of the standards by DHHS within two years or less, and, following the adoption, provide various measures designed to encourage rapid adoption of the standards by nearly all health care providers. These measures may include direct incentives, such as requirements that all health plans implement the standards for all transactions, or indirect incentives, such as requirements that all transactions regarding Medicare patients be filed electronically. The incentives may also be provisional: they may direct the Secretary to assess whether sufficient numbers of health plans are utilizing the standards and to require full participation, should it prove to be cost-effective. Most bills include exceptions for small hospitals and those that can show they are in the process of installing an adequate information system. Some of the bills override state laws requiring the maintenance of paper-based patient records.

Several bills seek to establish national or state databases of health information for quality assessment purposes, control of fraud, or tracking disease patterns.9 Other bills would authorize grants

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6 This committee is now known as the House Committee on Commerce.
for rural telemedicine efforts\textsuperscript{10} or establish a telemedicine commission to formulate plans for widespread implementation of telemedicine.\textsuperscript{11}

Finally, there have been efforts in both the 103\textsuperscript{d} and 104\textsuperscript{th} Congresses to reform and deregulate telecommunications.\textsuperscript{12} Such reforms may affect the price of telecommunications services and, therefore, help determine the feasibility of incorporating telecommunications into health care delivery on a large scale. In addition, current bills have certain direct influences on health care, including a requirement that prices for telecommunications service to rural health care providers be comparable to those for urban providers.\textsuperscript{13}

\section*{REPORT SUMMARY}

\textbf{Scope of the Analysis}

In chapters 2 through 5, this report discusses some of the challenges and opportunities for using information technology to improve the health care system. First, it addresses the potential impact of information technologies on health care delivery and introduces a variety of technologies that are being used to collect, organize, and share clinical information needed for providing patient care. The report then explores the exchange of health information for administrative purposes among the many stakeholders including providers, payers, employers, consumers, and government agencies. It discusses how the quality of health care might be improved by providing health care professionals with high-quality information and decision support tools at the point of care. Finally, the report explores the potential for addressing the needs of those in rural or other underserved areas through telemedicine.

Advanced information technologies offer an array of other possibilities for influencing delivery of health care services. It was impossible to address all applications in this report. Those selected were viewed as having the most potential for decreasing costs and improving quality and access in health care. Particular emphasis is placed on administrative simplification, quality assessment, and telemedicine, as specified by the congressional committee requesting the report. The report also briefly mentions the potential for telecommunications to assist consumers in becoming better informed and more involved in decisions affecting their health care, and points to the need for additional study. Emerging applications of information technology, including remote surgery and virtual reality applications, were not considered, nor were issues related to the reform of medical education to include greater use of information technology. These are, however, fertile areas for future research.

Before computers were introduced into the health care delivery system, clinical and administrative records were kept separately in paper form, patient utilization of services was rarely scrutinized systematically, and clinical information was seldom exchanged between business organizations (or even among the various clinicians an individual might see). Thus, paper-based technologies and common organizational policies worked along with various state laws to provide an ad hoc level of protection for individual privacy that is clearly inadequate in the emerging world of com-

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puterized patient records, integrated delivery services that operate on a nationwide basis, and instant electronic messaging. New combinations of legislative protections and technical safeguards will be necessary to protect individual privacy as health care information is computerized and standardized. These issues are discussed briefly throughout this report, but were discussed in detail in the OTA report *Protecting Privacy in Computerized Medical Information.*

The issues and policy options that emerge from each chapter of this report are briefly summarized in the sections that follow. First, however, two key themes are introduced that echo throughout the chapters. These are *cost containment* and *standards development,* and they reflect congressional concerns about containing health care costs and enabling administrative simplification that are manifest in the bills of the 103d and 104th Congresses.

### Cost Containment

Reducing the cost of delivering health care is perhaps the prime motivation for congressional interest in exploring the use of information technology. Anticipated cost savings are based on analogous reductions in transaction costs for industries such as banking—which built information infrastructures supporting automated teller machines and point-of-purchase credit card verification—and on the increase in productivity and product quality in domestic manufacturing industries associated with just-in-time inventory control, continuous quality improvement, and other techniques that are highly dependent on information technologies. Although similar efficiencies and improvements may be possible within the health care system, the magnitude of the savings is very difficult to predict for several reasons.

Most cost containment predictions maintain the traditional fault line between administrative information and clinical information. Administrative processes include activities such as transmitting and processing claims, utilization review, purchasing supplies and tracking inventory, paying bills, managing internal finances, negotiating contracts, complying with regulations, and controlling quality. Administrative costs of providing health care have been estimated at between $108 billion and $135.1 billion per year in 1991, or between 12 and 15 percent of the health care bill. Estimates of annual savings that could be realized through increased use of information technology in administrative functions have ranged from $5 billion to $36 billion, or enough to reduce administrative costs between 0.5 and 3.6 percent.

These estimates, discussed in more detail in chapter 3, may be somewhat optimistic because they assume rapid adoption of electronic data interchange and high rates of market penetration that do not appear to be materializing. The deeper problem with such predictions is that they are often based on merely converting all transactions within the existing system of fee-for-service health care to electronic form. However, the shifting landscape of health care delivery patterns cannot be treated as a perturbation within a more rapid process of digitizing health information. Such digitization did not happen over the past two decades despite the availability of increasingly capable computer and telecommunication systems; indeed, several organizational and technological impediments (discussed in chapter 2) make it likely that widespread digitization will happen only in

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synergy with the progressive adoption of managed health care practices and development of integrated service delivery systems.

A second class of economic considerations concerns the effectiveness of encouraging specific information technology implementations. These are of concern to Congress for purposes of guiding procurement decisions and research priorities. In recent years, the field of economic evaluation of medical technologies has expanded rapidly. Rising spending on health care has stimulated the use of formal techniques such as cost-effectiveness analysis and cost-benefit analysis to assess the cost and health effects of using particular medical technologies.

Cost-effectiveness analysis (CEA) has emerged as the most popular technique for economic evaluations. CEA involves a structured, comparative evaluation of two or more health care interventions. Analyses are designed to show the relationship between resources used (costs) and health benefits achieved (effects) for given technologies or programs. In CEA, the cost per specified health effect, such as lives saved or quality-adjusted life-years saved, is calculated for particular technologies or programs. If the ratio is measured similarly for different technologies or programs, the cost per effect can be compared. Formal CEA involves a number of explicit steps, including:

1. identifying the perspective of the study,
2. identifying the competing interventions,
3. defining costs,
4. defining effects,
5. discounting future costs and effects to their present value,
6. adjusting for quality-of-life factors,
7. analyzing the incremental costs and consequences of one option over another, and
8. examining uncertainties underlying the analysis.

In cost-benefit analysis (CBA), the net costs of an intervention are compared with the net savings: the benefits of a program or technology are expressed entirely in monetary terms. Because the benefit of medical technology generally involves health effects such as life-years saved, CBA requires that these effects be valued in monetary terms. One of two techniques—the human capital approach or the willingness-to-pay approach—is generally used to measure benefits. The human capital approach considers the value of a human life by estimating an individual’s projected future earnings. The willingness-to-pay approach considers how much individuals are willing to pay for a reduction in the risk of death or illness.

Applying the formal techniques of CEA and CBA to information technology applications in health care is difficult for a number of reasons. Some of the difficulties are general to all medical technologies: the competing alternatives for a technology are not always known; a technology may be cost-effective in some patient groups and not in others; technologies constantly undergo change; there are no standards on how to define costs (e.g., whether and how to consider indirect costs such as productivity losses, or intangible costs such as pain and suffering); there are no standards regarding the length of patient followup time to consider; analysts differ in their use of methodologies by which to adjust health effects for quality-of-life factors; and there are many uncertainties underlying such analyses. A general problem with CBA involves trying to place a monetary value on reductions in mortality or morbidity.

Beyond these general difficulties, evaluating information technologies presents some unique problems. It is difficult to conduct comparative studies because system features and levels of service vary widely across institutions and users. In addition, many applications have been in existence only a short time. Information technologies and applications change frequently, making analyses difficult—and making even some well-conducted analyses quickly obsolete. In general, it is difficult to identify and quantify appropriate costs, savings, and health effects. For most evaluations of information technology, direct costs would include equipment and operating costs, the value of the technician’s time, and the cost of maintaining equipment. However, it is hard to accurately identify and quantify indirect costs such...
as productivity gains or losses. In general, it is very difficult to tie the use of information technologies to health consequences.

As a result of these limitations, most existing economic evaluations do not constitute formal cost-effectiveness or cost-benefit analyses. Instead, most have attempted to estimate savings in terms of productivity gains to the system. Some have also speculated about how various applications will ultimately influence patient care. The design and scope of such analyses vary widely across studies, as does the level of rigor.

Congressional Options
Recognizing that implementation of information technologies will be an incremental process, Congress may wish to attempt to evaluate the possible systemic savings associated with implementation of information technologies in a way that recognizes the shifting patterns of health care delivery. Alternatively, Congress could evaluate, for administrative purposes, the costs and benefits of implementing various specific technologies or sets of technologies. These are difficult challenges. However, should Congress wish to pursue such analyses, it could direct agencies or congressional support services to implement one or more of the following options:

**OPTION 1:** Analyze systemic savings that might be associated with implementation of information technologies and related changes in health care delivery systems using realistic estimates for the pace of implementation.

**OPTION 2:** Conduct or fund research to evaluate the costs and effectiveness of individual information technologies, such as order-entry systems, clinical protocols, and electronic interchange of claim and payment information.

**OPTION 3:** Evaluate the potential for synergies between information technologies by funding research in the implementation of multiple simultaneous applications in test and control facilities.

**OPTION 4:** Establish baseline data for the costs of current information structures in the health care delivery system so that future implementations can be objectively evaluated.

Given these possibilities for cost-benefit analyses and systemic cost analyses, it should be noted that some stakeholders who contributed to this assessment indicated that *rigorous cost-benefit or cost-effectiveness analyses would not play a major role in their decisions to implement information technologies*. Rather, these technologies and systems of technologies were considered by many stakeholders to be as fundamental and as immune to cost-benefit analysis as the telephone: adoption of the technologies would be necessary to remain competitive in the health care industry.

### Standards Development

The second major theme that recurs throughout this report is the central role of standards development for systematizing the compilation and exchange of health care information. One value of digitized health information is that it can be manipulated quickly and accurately by computers without human intervention. The accuracy, speed, and cost of machine-processing are adversely affected by novelty, diversity, and frequent changes in the rules. Until standards are in place and compliance is widespread, costly activities—such as maintaining multiple formats for health care information, dealing with exceptions, and developing new interface software as new proprietary approaches to managing health information become fashionable—will continue to offset some potential savings of processing health care records and transactions electronically.

Standards development is an ongoing process. A number of organizations are working on standards for the content and format of electronic health information. Standards for the format of billing and core insurance transactions are well developed, and the Health Care Financing Administration (HCFA) has adopted some of them. Another area of standardization that could facilitate electronic transactions is a system of unique
identifiers for individuals, providers, and sites of care. At present, each provider uses its own numbering system, which can create confusion when health information is exchanged between different institutions.

The development of technical standards is primarily a private-sector activity. However, it could be accelerated through federal participation in developing standards that would encourage information exchange and protect the privacy of participants in the health care system, and through expeditious implementation of such standards in all federal health care matters as a catalyst for their adoption by the private sector. This should not be construed as a call for federal agencies to independently establish standards for implementing information technologies—such efforts would almost certainly fail to meet the needs of various stakeholders. Rather, federal agency participation in existing standards activities would preempt duplicative development of federal regulations and requirements. Further discussion of standards appears in individual chapters of this report.

Information Technologies for Transforming Health Care

The potential for new computing and telecommunications technologies to reduce the cost of delivering health care, while facilitating broad structural changes in the health care industry, may presage a rapid expansion in the application of information technologies to the health care system. Chapter 2 charts the technological and organizational factors that will help guide the path of that expansion should it occur.

Policy Issues

Many of the practical frustrations encountered by participants in the health care system can be traced to the inability of current information systems to provide accurate, timely information where it is needed in the health care process. Poor information mobility has become an impediment to efficient delivery of high-quality health care. This impediment becomes more prominent, expensive, and problematic for health care delivery organizations as they grow larger and more complex. One approach to solving this problem is to liberate health information from its traditional paper medium by creating, transmitting, and processing it through more flexible electronic means. Electronic information can be used again and again, in different forms for different purposes. It can be reformatted easily and transmitted cheaply once the infrastructure to do so is in place.

Chapter 2 identifies the broad currents of information flowing within the health care system, and then describes various approaches to computerizing clinical information within hospital and ambulatory care units. One portion of this clinical information is the patient’s medical record, which has conventionally been kept as a thick folder of paper forms and films. The chapter describes the design of paper recordkeeping systems and the reasons they are inadequate for documenting care in an integrated health care delivery organization. It discusses ways that this information might be digitized and then disseminated (with appropriate security measures) through standardized communications protocols.

A diverse suite of key computer and communication technologies supports the digitization and dissemination of clinical records. The chapter describes technologies for: a) capturing data as it is generated by caregivers and the machines they use to monitor and treat the patient; b) compressing, storing, securing, and retrieving data; c) networking and telecommunications technologies sharing information; and d) refining data and comparing data streams so computers can support medical decisionmaking. Insight and wisdom must somehow be culled from an overwhelming flood of bits and bytes.

This suite of advanced information technologies is also the context for discussions in subsequent chapters of the report that address administrative health data management, quality assessment and decision support, and delivering health care services and information at a distance.

Congressional Options

Many of these core technologies have been developed by the private sector for nonmedical pur-
poses and will be adopted within the health care system as needed. Nonetheless, Congress may wish to consider certain policy options that could encourage harmony in how that adoption proceeds.

**OPTION 1:** Support standards-setting activities.

Congress could direct relevant agencies to supply personnel to actively participate in standards-setting meetings. This would proactively obviate any federal regulatory activity that might be at odds with consensus standards by making sure that government interests are represented within the standards-setting process. Congress could also provide financial support for the process, including funding research support to help resolve any technological roadblocks that impede standards development. Congress could also direct federal agencies to set aggressive schedules for implementation of consensus standards in their own health care delivery and administrative activities as a catalyst for similar private-sector action.

**OPTION 2:** Fund and coordinate research efforts to overcome specific technological barriers.

These efforts could include research into human-computer interface technologies for use in health care settings and research into large-scale, open architecture implementations of information technologies in health care settings.

**OPTION 3:** Coordinate federal efforts to implement health care information technologies.

The agencies or committees charged with this coordination could:
1. establish procedures for expediting approval and distribution of medical software;
2. establish mechanisms (or support similar private-sector efforts) for reviewing and disseminating clinical protocols;
3. advise Congress on specific needs of the medical, technical, and consumer communities with respect to legislation establishing regulations and policies pertinent to information technologies; and
4. set national standards for patient and institutional identification numbers and security procedures to be used with patient records.

**Networks for Health Administration**

Chapter 3 explores the exchange of health information among the many stakeholders—providers, payers, employers, consumers, and government agencies—particularly for administrative purposes.

**Policy Issues**

As part of a larger effort to reduce costs, improve quality of care, and improve access to health care, efforts to effect administrative efficiency through greater use of electronic commerce in health care are an important component. Today, about 75 percent of hospital claims are submitted electronically, the vast majority of these being Medicare claims submitted to HCFA. Physicians submit some 47 percent of their Medicare claims electronically, but only about 16 percent of total claims. Between some payers and providers, the process of billing and being paid has been totally automated, with the organizations exchanging electronic claims, remittance advice (documents that explain how much of the claim is paid), and electronic funds transfers. However, such levels of automation are still unusual. Electronic claim services help providers deal with the multitude of different formats and requirements of payers. They offer software and services for translating and reformatting claims and other electronic transactions among the 400 or so different systems in use.

Compared with a paper-based system, it appears that electronic information reduces costs for some users. Most of the estimates for savings re-

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sulting from the use of information technology are based on cost reductions in payer-provider transactions resulting from automation in a fee-for-service environment. Managed care organizations can have equivalent transactions that presumably will cost less using information technology. However, the major savings that are expected to accrue from managed care come from better management of both resources and patient and clinician behavior—for example, reduction of unnecessary services. Information technology should assist in this as well. For example, having up-to-date patient records available at the point of service should reduce duplicate testing or the provision of nonallowed treatments. While it has been argued that information technology fosters better management, actual evidence of its contributions to cost reduction in this area is difficult to find.

Community health information networks (CHINs) facilitate exchanges of clinical or administrative data among providers and payers in a particular community or region. CHINs can help offset the lack of standardization by providing translations and interfaces between incompatible computer systems used by different network subscribers. Some networks, often called CHMISs (Community Health Management Information Systems), may also maintain a repository of administrative information for use in performing outcome research and quality assessments of providers and insurance plans in the community. At this point it is not clear whether community networks, which offer service to competing providers in the community, will survive as more vertically integrated health care organizations build proprietary information networks.

While exchanging health information electronically offers advantages, it also raises fears that privacy and confidentiality of health information may not be protected. Many consumers already fear that too many people have access to their health information. Most information needed for health care administrative transactions comes ultimately from the patient record. Clinical information in coded, abstracted form becomes administrative information. The provider attempts to capture, either through manual or automated means, everything that is done for the patient during a stay or visit, and to document information about resource utilization and costs in order to prepare an appropriate bill. Electronic patient records are under development in many locations throughout the country. In addition to technological and organizational barriers, there are a number of regulatory and legal barriers to complete implementation of electronic patient records, including conflicting state laws and regulations about how patient records must be maintained and the way privacy and confidentiality of records should be protected.

Health information is not limited to the patient record. Rights of patient access and procedures for protection of privacy and confidentiality are not clearly defined for secondary and tertiary users of health information (e.g., payers, researchers, and organizations maintaining health data repositories) under federal or most state laws. While most health care is local, in that people usually see caregivers in their own communities, health information often needs to cross state lines because the payer, provider, patient, and/or employer may be in different states.

**Congressional Options**

Savings may be available to the health care system as a whole as a result of universal implementation of electronic medical payments. However, at current implementation rates, universal compliance may not be achieved for some time, if ever. Getting started with electronic commerce requires a solid organizational commitment and a significant investment in equipment, software, process redesign, and education, but some organizations have weak financial incentives to make the investments needed to institute electronic payments. Others are forging ahead, unwilling to wait for standards. The health care industry in the United States is not organized as a “system” with a central focus or consensus on how to deal with system-wide problems. The different parts of the fragmented system have diverse incentives, and efforts by participants to control costs in their own area can tend to increase costs elsewhere. However, these shifted costs are so subtle and spread
over so many participants in a complex system that they are difficult to quantify.

The federal government has provided some leadership in helping the health care industry move toward greater use of electronic information, and may wish to continue this leadership role. There are three major areas in which government action might be considered: 1) providing leadership in the adoption of standards for electronic medical payments and other transactions and exchanges of health information; 2) establishing a system of unique identifiers for people, providers, and payers; and 3) establishing a more consistent regulatory environment for interstate exchanges of health information.

**OPTION 1:** Continue to influence the standardization of health care information primarily through the federal government's role as a major insurer.

The Health Care Financing Administration’s (HCFA’s) adoption of claims submission standards, along with incentives such as faster payment of electronic claims, has already been instrumental in encouraging some payers and providers to begin use of electronic payment systems.

**OPTION 2:** Require the adoption of industry-developed standards for core electronic transactions, including minimum and maximum data sets, and set timetables for their implementation.

If it is believed that HCFA’s influence alone will not ensure high enough levels of participation in a standardized electronic health payment system, then a more active federal role may be considered. A corollary to this option may be:

**OPTION 3:** Charge a government agency with responsibility and authority to set standards and data definitions for administrative transactions in consultation with industry groups, and to manage changes to standards over time; alternatively, create an agency or commission for this purpose.

**OPTION 4:** Establish a system of unique identifiers for patients, providers, and sites of care.

A national system of electronic commerce for health information will operate more smoothly if there is a better system for uniquely identifying participants in that system, both to prevent duplication and loss of information and to facilitate coordination of benefits when multiple providers and payers are involved in a patient’s care. Because of its national reach, the federal government may be in the best position to establish systems of identifiers.

In order to create a consistent legal and regulatory environment for electronic health information, Congress may wish to consider the following options:

**OPTION 5:** Encourage the passage of uniform state legislation with regard to privacy and confidentiality, allowable storage media, and standards for health information.

A number of industry groups have been working with state governments to encourage adoption of uniform legislation, and the Department of Health and Human Services has been assigned the lead role in designing model state privacy laws. An alternative or supplement to this option may be:

**OPTION 6:** Establish federal legislation and regulation regarding privacy and confidentiality of medical information, storage media for patient records, and standards for storage and transmission of medical information.

Additional federal legislation may be necessary as a framework for state legislation, or to replace state laws, if the process of revising legislation on a state-by-state basis is seen as ineffective or too time-consuming.

**OPTION 7:** Charge a government agency with responsibility to oversee the protection of health care data; provide ongoing review of privacy issues; keep abreast of developments in technology, security measures, and information flow; and advise Congress about privacy matters in the area of health care information.
Because of the importance of privacy and confidentiality to the public, the continually changing uses for health information, and the constantly changing nature of threats to privacy and confidentiality, it may be necessary to establish one organization as an ongoing locus of responsibility.

**Improving the Quality of Health Care**

Chapter 4 finds that advanced information technologies—computer-based patient records, structured data entry, advanced human-computer interface technologies, portable computers, automated data capture, online query, knowledge-based information systems, and computer networks—can potentially improve the quality of health care by enhancing clinical decision support, and by improving data for assessing both the effectiveness of health services and the performance of health care providers and insurance plans.

Information technologies could facilitate faster and easier collection of information about the patient and the health problem at hand. Portions of that information could be entered by clinicians at or near the point of care, captured directly from diagnostic and monitoring equipment, or entered by the patient prior to care. Technologies such as relational databases with online query could support faster and easier search and retrieval of previously collected information about the patient, as well as information from local or remote knowledge bases. Development of computer-based clinical protocols and other forms of clinical decision support systems (CDSSs) that apply decision rules and other knowledge-based approaches to information about the patient and health problem at hand could recommend diagnoses, tests, treatments, and preventive care. They could also lead to more rigorous construction and analysis of measures of service effectiveness and performance of providers and plans. Computer networks, high capacity telecommunications, advanced human-computer interface technologies, and improved graphics software could lead to more flexible organization and display of this information as appropriate for individual clinicians, and more rapid and widespread dissemination of the results of performance measures to various parties.

Empirical evidence demonstrating the ability of these technologies to achieve these goals is limited, mixed, or incomplete. Moreover, concerns have been raised about possible adverse effects on the quality of health care arising from these technologies, including:

1. incorrect parameters or criteria, or omitted or altered steps, in CDSSs that could lead to inappropriate care;
2. excessive reliance on monitoring equipment and CDSSs, which could undermine the ability of clinicians to exercise professional judgment in nonroutine cases and reduce the interpersonal aspects of patient care (the “quality of caring”); and
3. the temptation to use readily available administrative data for assessing the effectiveness of specific health services or the performance of providers or insurance plans.

If the data are incomplete or inaccurate, the results could be misleading.

**Policy Issues**

The private sector has been largely responsible for the development and application of information technologies in clinical decision support and performance assessment of health care providers and insurance plans. The federal government’s role has mainly involved:

1. developing information systems and performance measures for its own health insurance and health care delivery programs, most notably Medicare;
2. funding of intramural and extramural research and demonstration projects; and
3. participating in voluntary standards-setting activities with private-sector organizations.

All of these activities in both the private and public sectors are likely to continue, with some increasing and others decreasing. In an era of budgetary and regulatory restraints, however, major new government initiatives, such as funding for
technology development or mandated regulation of clinical information systems, are unlikely. It can be argued that this is appropriate—in other words, that the federal government should not interfere in private market decisions regarding the selection of new technologies or their applications.

On the other hand, the federal government—specifically HCFA—is responsible for ensuring the quality of health care rendered to Medicare and Medicaid beneficiaries. Recent efforts to move more beneficiaries into managed care have underscored quality concerns, given the expectation that capitation creates an incentive for underservice. Several policy issues regarding the potential impact of information technology on the quality of care delivered to Medicare and Medicaid beneficiaries deserve the attention of federal policymakers.

The foremost issue is the extent to which clinical information systems actually change clinical practice patterns and patient outcomes, and whether those changes are beneficial to providers and patients. Empirical research on this issue remains limited, mixed, or incomplete, and more solid evidence regarding these impacts needs to be obtained. To pursue such research, Congress could consider the following options.

**Congressional Options**

**OPTION 1a:** Maintain or increase funding for HCFA to develop and evaluate performance assessment methods and systems suitable for Medicare and Medicaid enrollees, using intramural research and extramural grants and contracts to private sector organizations for research and demonstration projects as needed.

**OPTION 1b:** Assign the task of coordinating the development and evaluation of performance assessment methods and systems and clinical information systems to a single federal agency.

**OPTION 1c:** Reduce funding for development and evaluation of performance assessment methods and systems and clinical information systems, and direct HCFA to employ performance assessment methods and systems developed and evaluated in the private sector, with minimal adaptation.

Until more solid evidence is available regarding the effectiveness and safety of existing clinical information systems and the reliability and validity of performance assessment systems, more drastic action—such as mandating the testing and certification of all such systems—is probably not justified. Legal questions regarding who should be held liable in situations in which such systems lead clinicians to make decisions that harm patients are probably best left to the courts to resolve.

Assuming that clinical information systems are found to be effective and safe in terms of their impacts on practice patterns and patient outcomes, the next set of issues focuses on the most efficient means of developing and implementing those systems.

One issue regarding government involvement in the development of standards and technology concerns the classification and coding of health services. Many major payers currently employ

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18 The state governments share responsibility for the Medicaid Program with the federal government.

19 Given a fixed payment per plan member, providers may be tempted to minimize the volume and/or intensity of services rendered for each patient.
two separate systems for coding health services: ICD-9-CM for billing by inpatient hospitals and other institutional providers, and CPT-4 for "professional" billing by clinicians and other non-institutional providers and suppliers.

For payment and other purposes, services rendered by a clinician in an inpatient setting must be coded using both of these systems, creating additional costs for providers. For many services, however, the codes in ICD-9-CM cannot be equated ("crosswalked") with those in CPT-4 because of substantial structural differences between the two coding systems. Moreover, both ICD-9-CM (Vol. 3) and CPT-4 have serious technical limitations, such as overlapping and duplicative codes and inconsistent and noncurrent use of terminology. Most importantly, neither has adequate room for expansion, so both are running out of codes as new services are created or different uses of existing services are distinguished. In addition, neither system provides sufficient clinical detail to support the creation of the kinds of databases required to accurately assess patient outcomes using advanced information technologies.

Citing these and other problems, the National Committee on Vital and Health Statistics, an advisory body to the Secretary of Health and Human Services, has recommended developing a unified classification and coding system for health care services. However, in 1994, even HCFA reaffirmed its intention to continue this dual coding system policy in its Medicare and Medicaid programs, despite the substantial barriers this poses to efficient information processing and analysis.

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**OPTION 2a:** Provide additional funding for intramural and extramural research on the feasibility of developing a single classification and coding system that could be applied to all health care services performed by all providers in all settings.

**OPTION 2b:** Establish a new executive branch program to develop a unified service classification and coding system.

**OPTION 2c:** Once a unified service classification and coding system is developed, mandate that all federal agencies that manage health insurance and health care delivery programs use that system in those programs.

**OPTION 2d:** Provide minimal funding for monitoring and facilitating private sector development of a unified service classification and coding system.

### Telemedicine: Remote Access to Health Services and Information

Telemedicine can be broadly defined as the use of information technology to deliver medical services and information from one location to another. The use of telecommunications to deliver health care services and exchange information is not new. Chapter 5 discusses how recent technological advances—such as fiber optics, integrated services digital networks, and compressed video—have eliminated or minimized some of the problems (e.g., poor quality images and slow transmission speeds) that limited earlier applications.

Currently, there is much interest in the potential of telemedicine to lower costs, improve quality, and increase access to health care, especially for those who live in remote or underserved areas. Pilot tests are also under way to test the feasibility of delivering a variety of services directly to consumers in their homes.

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Although there are no studies that prove the cost-effectiveness of telemedicine, in some cases it would seem to have the potential to reduce costs for some participants. For example, telemedicine can eliminate the time and wages lost at work and traveling expenses incurred when specialists and/or patients have to travel for consultations. In addition, keeping patients in their own communities can increase revenues for local hospitals and decrease the cost to patients. The cost of a bed in a community hospital is considerably less than in a large medical center. Costs might also be reduced by staffing hospitals and clinics with allied health professionals, such as nurse practitioners and physician assistants, who would deliver services where there is no resident physician. Overall costs also could be lower using telemedicine if it allows patients to be seen earlier, thus preventing the need for later, more costly care. Using telecommunications to deliver services directly to the home would also reduce the costs of travel, as well as the pressures on clinics, emergency rooms, and doctors’ offices.

In the short term, however, costs could increase. Telemedicine could add an extra step to the process if the patient still requires referral to a larger medical center. If it improves access to care, there may be increased use of health services as more people take advantage of their availability. If reimbursement for telemedicine services becomes widespread, the system may be vulnerable to abuse through overuse or fraudulent claims. Cost is not the only criterion, however. It is important to consider the “value” of delivering services to those who might otherwise not get them at all because of their physical location.

Telemedicine can increase access to health care for populations in rural or inner city areas. It can do so by making these areas more attractive to health care providers by giving them immediate electronic access to up-to-date information and resources, specialists for consultative purposes, continuing medical education, and other colleagues. Enabling local hospitals to remain economically viable by keeping patients in their own communities is another benefit for access, as well as for the economic stability of the community.

Telemedicine appears to have the potential to improve the quality of care, but this has not yet been proven. It can provide faster, more convenient treatment and minimize the disruption of the patient’s life. By reducing the need for referrals, the continuity of patient care is ensured. The quality of care may be better for a patient who has the benefit of family support in the local area. For providers, ready access to information to help them make more informed decisions will improve the quality of the care they deliver. Electronic access will help them stay up to date and enable them to receive continuing medical education credits without leaving their communities. Some believe that the establishment of clinical practice guidelines for telemedicine could help to provide a more consistent level of care.

While telemedicine has been practiced for 30 years, its current iteration is still in the early stages of development. It will take a number of years before it is used widely enough and evaluated sufficiently in terms of its effectiveness and efficiency for definitive statements to be made about its overall value and recommended uses. Like all new technologies, there will be impacts that cannot be anticipated in advance. Rigorous evaluation studies are needed to determine telemedicine’s potential benefits, and such research is currently being supported by a number of federal agencies. The results should provide policymakers with the data they need to make decisions about the efficacy of telemedicine. Proposed federal budget cuts, however, are likely to have a negative impact on telemedicine research efforts.

**Policy Issues**

While the use of telecommunications in delivering health services has great potential, it also raises a number of issues that need to be resolved if telemedicine is to thrive. In general, patient consultations using telemedicine are not reimbursable (except for teleradiology and telepathology). This will have a negative effect on its diffusion until HCFA promulgates a national policy. One of the reasons for HCFA’s reluctance is the fact that there is a lack of research available to support the
safety, efficacy, clinical utility, and cost-effectiveness of telemedicine.

Another issue is the cost of the telecommunications links required for telemedicine. In many rural areas, the communication infrastructure is unable to support the bandwidth necessary to carry the signals for telemedicine using two-way interactive video. In addition, the costs of connections between local and long-distance telecommunication carriers can pose a significant barrier to telemedicine projects. Under the existing tariff structures, telephone calls placed to locations inside the local access transport area boundaries are often more expensive than those placed outside the same service area.

Telemedicine raises some difficult legal and regulatory issues as well. Remote diagnosis and treatment across state lines could bring different laws and regulations into play. A previous OTA report found that the present legal scheme does not provide consistent, comprehensive protection of privacy in health care information, whether it exists in a paper or computerized environment. Clearly the privacy implications for telemedicine will continue to receive careful scrutiny. Physician licensing becomes an issue because telemedicine facilitates consultations without respect to state borders and could conceivably require consultants to be licensed in a number of states. This would be impractical and is likely to constrain the diffusion of telemedicine projects. Telemedicine may, in fact, decrease the threat of malpractice suits through improved recordkeeping and databases, and the fact that taping the consultations will automatically provide proof of the encounter. However, it may also raise other liability issues, such as the lack of a “hands-on” examination by the consultant.

**Congressional Options**
Responsibility for telemedicine policy is shared among federal, state, and local lawmakers, and many of the decisions affecting the diffusion of telemedicine are influenced largely by the private sector. Federal efforts to reform both the health care and telecommunications systems, each traveling its separate path, will have an effect on telemedicine’s progress.

Implementation of telemedicine is likely to proceed with or without federal support as providers recognize its benefits to their practices. However, federal government support will be required if it is to benefit those who need it the most—people living in rural and inner-city areas where market forces are unlikely to provide the services needed. In a time of tight fiscal constraints and shrinking research budgets, federal funding provided will need to be carefully monitored to ensure it is being used wisely. If Congress wishes to encourage the diffusion of telemedicine to help solve the disparities in health care availability, it can have the most impact in the areas of research funding and reimbursement for telemedicine consultations. The two are closely connected, in that formulating a standard reimbursement policy is dependent on obtaining satisfactory answers to many of the questions raised about telemedicine’s efficacy and cost-effectiveness. Congress may wish to:

**OPTION 1:** Continue to support demonstration and evaluation projects.

The research currently under way is crucial to answering many of the questions about the benefits of telemedicine. To ensure that projects are sustainable when funding ends, agencies need to build in certain requirements. This is currently achieved by requiring that grantees make a financial investment in the project, often through matching funds. Many of the current funding opportunities for telemedicine projects focus on rural areas. Telemedicine also offers potential for solving some of the problems of inner-city health facilities. After assessing these needs, Congress could target support for depressed areas where the needs are great and a limited investment might be highly leveraged.

Because the data that would support a uniform reimbursement policy for telemedicine consultations are not yet available, HCFA is moving slowly and deliberately in accumulating the necessary information on which to base a sound decision.
This seems a prudent strategy. Experimenting with reimbursement in a small number of demonstration sites will provide valuable insights that will eventually enable the agency to craft a careful policy based on actual results. Congress may wish to ensure that adequate funding is provided to support those experiments. As the results become available, Congress may wish to provide oversight and conduct hearings to determine what further action may be warranted.

Until recently, there was a lack of coordination of federal efforts in research, policymaking, and implementation of distance care. This has been remedied considerably by the creation of the telemedicine working group of the Administration’s Information Infrastructure Task Force.

The costs of implementing telemedicine can be a barrier to its diffusion, especially for small communities and facilities. To address this barrier, Congress may wish to:

**OPTION 2:** Create incentives for cooperative efforts and consortia.

In many small communities, it makes economic sense for groups to share the costs of implementing, operating, and maintaining a telecommunications network. For example, schools, medical clinics, libraries, social services, and others who would benefit from improved information services may need to join forces to get started. The Department of Defense and the National Aeronautics and Space Administration (NASA) have been leaders in research related to telemedicine applications, and the military has health facilities in a number of locations. In some sites the military has cooperated with civilian health care personnel to deliver services using telecommunications. Where possible, the expertise that exists in the military and NASA should be shared with the civilian sector. Agencies such as the Department of Veterans Affairs could also be involved in cooperative efforts with the civilian sector.

**OPTION 3:** Ensure that information about telemedicine is widely disseminated.

In many cases, those who might benefit most from telemedicine applications know very little about them. While information dissemination is increasing in a variety of formats, there is a need for a centralized, online database of telemedicine information. Such coordination might include creating an electronic clearinghouse that would provide a range of information about telemedicine projects, including funding opportunities, current projects, and people to contact for assistance and advice. Congress might wish to ensure that mechanisms exist, either in the public or private sectors, to widely disseminate research results and other information about telemedicine.

One of the goals of the IITF telemedicine working group is to investigate the feasibility of setting up an online database of telemedicine activities, and work is continuing to determine the best way to achieve this. Such a clearinghouse could be established in a designated federal agency within DHHS, such as the National Library of Medicine or the Office of Rural Health Policy. Alternatively, Congress could provide support for a private-sector group, such as the Telemedicine Information Exchange network at the Telemedicine Research Center, Oregon Health Sciences University. This option would avoid duplication of effort and provide a single site where telemedicine information could be maintained and obtained. However, it would also require careful consideration concerning the content of the database and how information would be structured and formatted. Any telemedicine clearinghouse would only be useful if kept up to date, and support for qualified staff would needed to be assured.

**OTHER APPLICATIONS**

The applications of information technology detailed in chapters 2 through 5 and summarized above were selected because of their potential to improve access to health care, improve the quality of care, and reduce the costs of delivering care. These were of particular interest to the study’s requesters. OTA was unable to undertake an in-depth analysis of a number of other applications of information technology that also have potential
for improving health care. Two are mentioned here—consumer health informatics and community networking.

**Consumer Health Informatics**

Consumer health informatics has been defined as “the study, development, and implementation of computer and telecommunications applications and interfaces designed to be used by health consumers.” The basic principle is that of empowering people to play a greater role in their own health care and to be active participants in decisions affecting their health. Information technology can be used to provide more health-related information to consumers, “the largest untapped resource for health care.” Taking measures to prevent illness and disease, by adjusting lifestyles or taking safety precautions, for example, could have a positive impact on the health care delivery system and allow people to lead healthier lives.

*Shared decision support systems* are designed to inform patient/provider decisions regarding prevention, diagnosis, management, and treatment, and ultimately to improve the quality of care and reduce costs. Choices are made collaboratively by patients and their caregivers. An example is the interactive video disk system developed at Dartmouth Medical School that allows men with benign prostatic hyperplasia and early stage prostatic cancer to share in decisions on their course of treatment. Some regard these computer-based systems as transforming the culture of the health care system to one in which patients, physicians, and other providers play equal roles in decisionmaking.

Information technology also could play an important role in reducing a consumer’s need for health care services. *Demand management* can be defined as the “the support of individuals so that they can make rational health and medical decisions based on a consideration of the benefits and risks of the options available.” Current examples include health risk appraisals, written and audiovisual media, telephone counseling services, and community resources. Although a comprehensive demand management system does not yet exist, information technologies can make interventions more available and effective, and provide a sophisticated, multipurpose information system based on a new concept of the individual health record. When developed, these comprehensive services will allow consumers to understand, choose, and evaluate health services in new ways, and could have a positive impact on health care costs and quality.

Information technology also fosters communication among people who can provide support and encouragement to those dealing with chronic illnesses or a medical crisis. There is a large and growing community of people using computers to provide help and support to one another to address a variety of concerns. For example, as of early

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23 Tom Ferguson (ed.), “Consumer Health Informatics: Bringing the Patient Into the Loop,” *Proceedings of the First National Conference on Consumer Health Informatics*, July 1993, p. 2. The Administration’s Information Infrastructure Task Force, Consumer Information Subgroup, defines consumer health informatics as “any information that enables individuals to understand their health and make health-related decisions for themselves or their families.”


27 Deborah Deatrick, Executive Director, Health Commons Institute, personal communication, June 9, 1995. See also Slee and Deatrick, op. cit., footnote 25, p. 1.


29 Ibid.
May 1995, America Online reported it had 148 scheduled self-help groups. Some of these groups address health-related concerns, such as diabetes, stroke, AIDS, cancer, or disabilities. Others support the caregivers of people suffering from Alzheimer’s disease or other debilitating illnesses. Nonprofit groups, such as the American Self-Help Clearinghouse, provide assistance and information to those wishing to set up an electronic support group or find out about such groups.

Information on a variety of online health resources can be obtained from the National Health Information Center. The CHESS system is an example of one that allows consumers to access information about their illnesses and to support one another using home terminals. Another is the Connect System, a computer and voice-mail system used to monitor inner city drug-using pregnant women in Cleveland, Ohio. At Case Western Reserve University, ComputerLink was a demonstration project that supported the caregivers of persons with Alzheimer’s disease and AIDS by delivering information, communication, and decision support, accessed through home terminals. (See ch. 5 for more complete discussion of these systems.) Future systems geared to the needs of consumers are likely to include interactive video to the home.

Participants in an OTA workshop in July 1994 had a number of suggestions regarding what actions are needed to foster greater electronic health resources for consumers. These included:

1. support research and development;
2. support wide access to the NII as it develops;
3. insist on good needs assessment for consumer applications;
4. incorporate medical informatics into the medical education curriculum;
5. support clinical trials of different ways of sharing health data;
6. reduce the cost of telephone links to electronic bulletin boards;
7. subsidize premarket development of tools that private corporations can use and resell;
8. facilitate the use of technology by managed care organizations;
9. educate, support, and train users; and
10. provide grassroots technology “set-asides.”

The Administration’s Information Infrastructure Task Force has a subgroup of representatives from federal agencies who are addressing consumer health information and the NII. This committee has coordinated the development of a draft white paper outlining key policy issues for the federal government to consider as the public increasingly relies on electronic means of information access and exchange. This paper was released for public comment at a federally sponsored national conference on networked consum-

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er health information in May 1995. It will serve as the cornerstone for Administration policy in applications technology development and use.

Key policy issues for the federal government identified in the paper include:
- the need to coordinate federal consumer health information dissemination efforts both within the government (federal, state, and local) and with private providers;
- assurance of privacy and confidentiality;
- assurance of the availability of information critical for public health;
- the need for research and evaluation of the impact of consumer health information;
- the role of standards in vocabularies and data transmission;
- information validity and integrity;
- assurance of telecommunications infrastructure for adequate information delivery; and
- education and training.

I Community Networking

Human services, including health care, are often delivered in a fragmented fashion, leading to duplication of effort on the part of providers and consumers. Telecommunications could be used to coordinate and streamline these services through community networking, enabling the providers of a wide variety of social services to share information and communicate with one another. An earlier OTA report discussed the role of the local community infrastructure—schools, libraries, senior centers, and town halls—in delivering federal services to citizens electronically, especially those in rural areas, small towns, inner cities, and people with special needs (see box 1-3). The difficulties of building an infrastructure can be a barrier, however. One group of researchers commented:

Although there is widespread endorsement of such proposed efforts as managed care and one-stop shop service delivery, the more difficult task in most communities is to build an infrastructure that supports such coordination with a holistic approach to service and care.

One example of a project using telecommunications and computer technologies to support and coordinate health and human services at the community level is the Community Services Network (CSN) in Washington, DC. This is a joint effort of the U.S. Public Health Service, Howard University School of Social Work, Rice University and Baylor College of Medicine, Macro International, Inc., United Seniors Health Cooperative, and Bell Atlantic Corp. Several communities across the country are currently exploring the development of CSNs. The Lawrence Livermore Lab in California is helping Macro and other partners develop test-beds to move CSNs from pilot to early operational status.

36 For a discussion of the role of information technology in strengthening community action, see Nancy Milio, Engines of Empowerment (Ann Arbor, MI: Health Administration Press, 1995).


39 Kevin Patrick, Department of Health and Human Services, personal communication, May 10, 1995.
OTA commissioned two grassroots computer networks to conduct computer conferences on the topic of electronic service delivery. Big Sky Telegraph (BST), headquartered in Dillon, MT, and the National Public Telecomputing Network (NPTN), headquartered in Cleveland, OH, conducted the conferences during late summer and fall of 1992. Lessons learned include:

1. The costs to users of grassroots computer networking can be minimized. Almost any personal computer (PC) and modem will suffice; high-end, high-speed equipment is not necessary. Online telecommunication charges can be reduced by copying messages to a PC and preparing responses with the telecommunications line turned off, and by using fractional rates and bulk purchase discounts. Use of equipment that transmits messages faster will reduce online charges further.

2. Any local community can have a community computer bulletin board. BST has, in effect, created six “Little Skys” where people can dial in with a local call—further reducing online costs. BST is a rural equivalent of the NPTN’s network of “FreeNets.” BST is a rural FreeNet. All you need is a PC, modem, telephone line, and inexpensive bulletin board software. And to further reduce costs, the “Little Sky” or “FreeNet” can dial up a host computer once a night at off-peak rates to copy or add bulletin board items.

3. Community computer bulletin boards really extend a sense of community. BST and NPTN, like CompuServe and Minitel, found that users participate as much for sociability as for content. Users seek a comfort level and degree of intimacy that is not always prevalent in the community-at-large. Computer conferencing also greatly reduces any biases due to sex, physique, disabilities, speaking ability, etc. It is a leveling technology in this sense.

4. Community computer networks usually get only limited support from the established government and business community. The BST and NPTN approach is low-cost and decentralized; the state and federal bureaucracies tend to favor higher cost, more centralized, or at least more controllable, approaches. Also the “not invented here” syndrome is evident. Each organization has a tendency to invent its own solution or approach.

5. Grassroots computer network utilities like BST and NPTN can facilitate local access to national computer networks that might not be otherwise technically feasible or affordable. If local residents find computer networks such as the Internet expensive or difficult to access directly, computer utilities can provide low-cost, user-friendly connections.

6. Grassroots computer conferencing works for children. Children as young as the third grade can use computer conferencing to learn keyboarding, e-mail, and the concept of communicating among a group electronically (even some first-graders can handle it).

7. Grassroots computer conferencing has significant potential for government service delivery. For example: a) agricultural extension services, b) small business assistance, c) international trade—global trade networks offer tremendous potential for locally based global entrepreneurial networking, d) Indian reservation services, especially for the Indian schools and hospitals, e) vocational education for displaced homemakers, f) job opportunities—potential for computerized catalogs of jobs and skill requirements, and g) public access to the legislative process.

8. Training is essential to computer conferencing success. It is important for first experiences to be positive in order to develop self-confidence. Help lines work, rather than forcing users to struggle through manuals. As confidence builds, users can do more themselves and handle more complex functions. Initially many people are not ready for searching databases; but eventually users will want to and can do searches.

9. Federal programs largely miss the potential of grassroots computing. The government does not have good mechanisms to support small, local innovators who lack a major institutional affiliation. Suggestions: mini-grants of up to $5,000 or so to local innovators; more flexibility in the National Science Foundation and other federal grant programs to support individuals and small, grassroots organizations; inclusion of grassroots representatives on federal advisory and peer review panels; technology showcases and demonstrations (e.g., fiber-to-the-school demonstrations in rural, economically disadvantaged areas).