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Business-Government Forum on Medical Information Networks and Technologies:

Potential Contributions to Health Care Reform And Requirements For Success

**A Report on a meeting of industry and health care experts held by the
Business and Industry Advisory Committee to the OECD**

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FOREWORD

On September 17 and 18, 1997, the Business and Industry Advisory Committee to the Organisation for Economic Co-operation and Development (BIAC) convened a Forum on medical information technology and its impact on health care. The Forum included speakers and participants from numerous countries who are involved in the study, development, or implementation of medical information technology, broadly understood. For two days, speakers addressed a range of subjects that included health care data bases and the internet, electronic medical health records, technology standards in health care, and the protection of private health care information in a world increasingly driven by the electronic transmission of personal data.

As this report makes clear, a general consensus emerged from this diverse group. First, advances in information technology have a direct and substantial impact on improving the quality and efficiency of health care services. Second, the integration of information technology into the practice and administration of medical care enhances the potential for the health care sector to become an even stronger engine of economic growth and job creation than it is today.

Nonetheless, as is explained in the pages that follow, there are many legal, regulatory, and institutional hurdles that must be overcome if medical information networks and technology are to become an integral part of every health care system. This report on the Forum is intended to provide an overview of these key issues and challenges with the hope that health care professionals and policy makers will better understand how they can take full advantage of the opportunities offered by medical information technology.

The Business and Industry Advisory Committee to the OECD was formed in 1962 to serve as an independent nongovernmental organisation representing the views of business and industry. It is comprised of the industrial and employers' organisations of the OECD's 26 member states. In its consultative capacity, BIAC informs the OECD of the private sector's opinion on various policy options.

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I. The Purpose and Rationale of the Forum

Few industries have felt the impact of technology as much as health care. Virtually every aspect of health care -- from a patient consulting a doctor in a private clinic to the administration of immense state health insurance systems -- has been touched by some recent advancement in medical or communications technology.

Most people readily recognise the role that technology plays in medical procedures and therapies. Sophisticated surgical procedures, new medical devices, advancements in drug therapy, and new tools in disease protection have all benefited from technological enhancements. Equally important, however, have been the advancements in *information technology* that have changed the way a doctor can communicate with a patient, a colleague, or an outside source of expertise. Similarly, the tracking of a patient's medical record, the processing of medical insurance claims, the training of new physicians, basic medical research, the study of how costs can be controlled or the dissemination of data about therapies, regulations, or disease management are increasingly dependent on the information technology available. The computer and the internet, once seen as purely managerial tools in medicine, are now indispensable vehicles for improving the quality of patient care.

Precisely because information technology has become so essential for health care, the Business and Industry Advisory Committee to the OECD convened this Forum. Two years ago, in a paper presented to the OECD High Level Conference on the «new welfare agenda,» Dr. Alain Sommer argued that the social protection system -- including health care -- should be rethought in terms of productivity. Productivity depends not only on reducing costs, but also on the creation of more efficient services to satisfy existing and new needs. To maintain a competitive, efficient, and socially equitable system, this paper argued, it is necessary to «create information networks specific to the social protection market.»

This Forum strived not only to examine how such information networks can be established, but also how they can influence the practice of physicians, how they can shape government health policy, and what challenges we face in absorbing new developments. While a full range of opinion was expressed during the day and a half proceedings, it immediately became clear that a consensus among the participants existed on at least two fundamental points. First, advances in information technology have a direct and substantial effect on improving the quality and efficiency of health care services. Second, the proper integration of information technology into the practice and administration of medical care enhances the potential for the health care sector to become an even stronger engine of economic growth and job creation.

Having recognised the promise of information technology and health care, the Forum devoted the bulk of its attention to the far more difficult questions of how to bring new advances into the health care systems of the OECD nations. On this front, there are many frustrations. Indeed, the paradox of contemporary health care would seem to be an industry that is at once so reliant on technology still has hospitals and doctor's offices relying on the pencil and notepad as the primary tools for recording patient health records. This paradox is easy to understand. Although nearly all of the OECD nations have undertaken significant health care reform measures in the past decade, the scope of reforms has not exceeded the frontiers of the nation. Changes to the National Health System in Britain have had little direct influence on medical practice in France. A new system of physician compensation in Sweden has no impact on billing practices in the United States. The reform of health care systems, in other words, has largely been local.

Information technology, however, offers the potential of changes reaching beyond national borders. With systems that can track patients' long-term medical records regardless of where they travel and consultations that can take place over video monitors thousands of miles apart, health care information networks transcend many of the barriers established by national regulation. Consequently, co-operation among countries is highly desirable. Achieving maximum efficiency requires that government and industry look beyond their own health care systems to see how they can take advantage of innovations in information technology occurring around the globe.

Creating a more open health care system, interconnected by information networks, gives rise to numerous questions: Who pays for these international information networks? Who is accountable for them? How do we insure that quality is maintained? How do we develop standards for equipment and practice? How do we obtain the data necessary to create networks with valuable information?

All these questions remind us that the issues surrounding medical information networks and health care reform require political and social change as much as they do technological innovation. Indeed, proceedings of this Forum made clear that the technology needed to create an integrated health care system based on information technology is already far advanced. The challenge is to put these technological innovations to use.

II. An Introduction: The Internet and Other Networks as Vehicles for Global Medical Information Technology.

The Forum's chairman, Dr. William Lowrance, opened the proceedings with an ambitious vision of global health care enhanced by information technology. He described a system in which all medical and health care records would be computer-based. Such a system would contain not only the medical records of patients and their interactions with physicians, but also every financial transaction, regardless of the system of payment. Using computers merely to store this information, however, is insufficient. True medical information networks require a system that can receive and distribute data to people who have appropriate access. That might include patients, providers, nurses, pharmacies, and specialists. Through a networked system, the efficiency of technology can be realised.

Information technology also produces something else indispensable to the long-term improvement of health care: more information. Nearly all advancements in the administration and delivery of health care depend on strong and reliable data bases. Unfortunately, good sources of information on patient histories, physician practice, and effective treatment are scarce. The goal of an information technology policy as it applies to health care must be to make the collection of data far easier. Good data is always a vital element of solid medical research. It is a necessary part of the drug development process and biomedical research. By broadening the opportunities to collect and aggregate data, medical information networks offer new opportunities for policy makers and health administrators to make objective decisions about beneficial and cost-effective treatments.

An extensive medical information network would give policy makers and practitioners new and invaluable tools. It would also introduce unprecedented conveniences and choices for patients. A patient's medical record could be portable and permit physicians -- once granted access -- to see an individual's medical history, rather than trying to reconstruct based on often fragmented recollections or an incomplete paper trail. Policy makers and researchers could compare practices and results from several different countries. Electronic medical records, electronic medical cards, and internet data bases

would give patients far more data about their own health and the options for treatment. As the Chairman of the Forum pointed out, all this information helps create a much truer market for health care. Yet he also warned that the pursuit of more integrated information networks within our health care systems raises new questions about the handling of information and the protection of privacy. No government can adequately promote advances in electronic medical information networks without addressing the privacy issues that come with them.

Mr. David Bryan, Vice President of EDS Corporation, discussed health care information as a market in which patients can become true consumers, making informed choices rather than merely consenting. Today, Mr. Bryan argued, the absence of comprehensive, integrated information technology in health care denies patients the ability to be fully informed consumers. The result is that cost, error, waste, and fraud are, regrettably, the most influential forces in health care systems. Bryan offered a number of disturbing illustrations:

- Every year 180,000 unnecessary deaths and 1.3 million injuries in the United States are incurred because of medical error.
- The U.S. Medicare program is burdened by approximately \$23 billion in fraud and abuse costs -- 10 percent of the total expenditure.
- Forty-five percent of Americans do not have adequate information about the proper use, dosage, or side effects of prescribed drugs they purchase -- a lack of information that costs \$75 million per year.
- In Britain, wrongly prescribed drugs are the most common cause for medical liability cases. From 1990 to 1995, the country's Medical Defence Union, the physician defence fund, disbursed £3.5 million in compensation for wrongly prescribed drugs.

These problems are a result of weak, inadequate, or non-existent information in the health care system. Many of them could be avoided by using technology that is already well advanced. Yet the difficulty begins when information is not captured when there is an interaction between a doctor and a patient. Further obstacles are the absence of information technology to transmit captured data and a lack of standards to allow one health care information system to talk with another. An additional stumbling block is the presence of too much data, which confuses analysis and evaluation.

These errors due to faulty information point to another problem all health care systems face: a demand for greater accountability. Patients, administrators, physicians, and policy makers are increasingly looking for the ability to validate the practices and expenses of the medical system. The current level of information, however, makes that hard to obtain. But in an increasingly competitive industry, this situation cannot last. Only those health care stakeholders who can provide information that confirms high-quality, cost-effective outcomes will succeed.

The future alternative, as sketched by Mr. Bryan, is a system of medical knowledge that promotes disease management based on solid data, higher outcome measures, shared information, and the creation of new knowledge through analysis. He outlined a scenario in which a child born in a hospital has all her birth information inscribed into an electronic medical record. Through the use of data bases, networks, and home computers, all future medical transactions are recorded: childhood vaccinations, adolescent medical episodes, prescription drugs, specialists seen in foreign countries, changes in diet, and physician diagnoses, comments, and prognoses along the way.

This vision is not as futuristic as it may sound. At the Mayo Clinic in Minnesota a private «intranet» system allows teams of doctors and nurses access to vital patient information, without having to reconstruct a patient history every time a new care giver has contact with the patient. Unlike the internet, the system is restricted to those authorised to have access within the clinic. Billing information is shared with another intranet system, known as «Mednet,» that serves the entire state of Minnesota. The systems have allowed the Clinic to reduce the processing time for a single claim from thirty minutes to 15 seconds. The immense expense reduction is readily seen.

The primary reaction from Forum participants to this call for an information-based health care system was a practical one: Why are we not already there? In the discussion, participants pointed to the numerous obstacles facing the adoption and expansion of advanced medical records. The most obvious are the standards for appropriate practice that differ from country to country. No universal practice guidelines exist that are internationally accepted. Even if such practice and treatment guidelines were written and used as the basis for a health information system, who would take responsibility -- and face liability -- for them?

A more fundamental problem is that many countries are slow to adapt technology (and health care has been slower to exploit technological advances than some other industries). In many cases, short-sighted government policy views information technology as an expense rather than a strategic health care tool that creates efficiency and improves access and quality.

Another issue raised at the outset (and reiterated throughout the Forum) is the privacy concerns created by any medical data base that contains personal health information. How much access to the data should be allowed beyond the physician? These privacy concerns are directly linked to the willingness of patients and their doctors to use medical information networks and electronic medical records. The expansion of such technological tools must be accompanied by the willingness of both patients and physicians to be co-operative participants.

In sum, the primary challenge facing the integration of information technology into health care systems is its acceptance by doctors, patients, and courts. This challenge is not technical, but social and political.

III. Applications and Assessment

How will the application of information technology effect the internal functions of health care institutions and the relationships among members of these institutions? How will their application improve quality and lower cost? What needs are fulfilled by information technology in health care? Do these advancements create new demands?

These questions were the focus of the next session of the Forum. Six speakers discussed the questions from the perspective of providers, insurers, government, hospitals and pharmaceutical companies.

The Opportunities of Telemedicine.

Professor Tore Schersten, the Head of International Affairs at the Swedish Council on Technology Assessment, began by reminding the participants that technology and health care was hardly a new

subject. He had attended a conference on the same topic in 1959 at Rockefeller University. The difference is that, in the late 1950s, computers were seen largely as a tool of medical management, a method for storing data. Today, information technology has a more direct and intimate impact on the doctor-patient relationship.

Telemedicine is the heart of much health care-related information technology. Its expansion is based on the premise that it can drive down health care costs while improving the range and quality of medical services. Medical consultations by telephone and telegraph have, of course, existed for decades. Today's telemedicine opportunities are far more diverse and ambitious. They include:

- **Teleradiology:** Information from magnetic resonance images or x-rays or similar radiology is transmitted from one location to another electronically where it is analysed or compared with previous data, saving considerable expense in time and transportation.
- **Telepathology:** Surgeons exploring a tumour during an operation can use electronic transmissions to send vital information to a pathology lab where, using a «telemicroscope,» pathologists can determine whether a tumour is malignant and advise the surgeons.
- **Virtual Reality:** Medical students and experienced physicians can learn new surgical techniques using interactive computers and holographic images. These virtual reality simulators are not unlike the simulators used to train pilots or tank commanders. As technology advances, this process will drastically reduce the steep learning curve that medical students training to be surgeons face -- and the errors that are often committed by the less experienced . In the future, it is possible that the first «operation» conducted by a young surgeon would never be on an actual patient.

As these techniques become a part of health care systems, the positive changes they could introduce are enormous. At the same time, they alter the relationship between the physician and patient. Traditionally, Professor Schersten explained, the doctor stood between the patient and the system. As telemedicine techniques become central to the practice of medicine, physician and patient become dependent on the integrity of the system. A whole new range of safety considerations comes into play. Accidents due to technical errors, for example, would be tremendously hazardous for telemedicine and would prove a major setback for its widespread acceptance. These considerations should be the primary focus of industry and government.

What is now missing is a more thorough assessment and evaluation of telemedicine practice. We do not yet know if some telemedicine practices are truly cost effective or what level of initial investment they would require. Legal, social, and ethical issues are also paramount. Above all, telemedicine requires a traditionally conservative medical profession to use technology that is already available. More assessment and testing of all aspects is critical to its widespread acceptance.

Creating Comprehensive Electronic Medical Records.

Compared with some telemedicine practices, the technology supporting electronic medical records is advanced. Yet it, too, finds that acceptance and support within health care systems is a stumbling block.

Dr. Alain P. Maskens of Health Data Management Partners in Brussels reminded the Forum that while computers are widely used in laboratories and medical libraries, many hospitals have 100 percent of patient medical records stored on paper. Even when great efforts are made to capture information about a patient's medical history, there is no system or standard process for securing that information. The lost opportunity for more efficient health care systems is obvious.

In the early 1990s, the European Union embarked on the «Good European Health Record Project (GEHR)» to create a standard architecture for an individual medical record. More recently, the European Standardisation Committee has produced a European standard for health care record architecture, in which some of the GEHR concepts have been adopted. Funded by both the European Union and a variety of health care industries, the GEHR project represented a \$5.2 million investment over a three-year period.

If an electronic medical record is to have maximum utility, it must:

- Create common, structured messages.
- Support a lifelong, comprehensive patient medical history that reflects all transactions between an individual and health care professionals.
- Support detailed analyses of these records in full clinical detail.
- Assure full portability.
- Accept a variety of ways for inputting information using a keyboard, mouse, magnetic pen, optical scanner, or voice.
- Integrate with local administration and billing practices.
- Integrate medical guidelines, disease management systems, decision support systems, etc.

Unlike electronic databases that support billing and claims information, patient medical information is often far more complex. Rather than a single processor, a patient may be seen by a large number of health care professionals who will rely on and contribute to a patient's record. The computer system must, therefore, be far more powerful. The GEHR has shown how such a system can work. What has been created is a system that is independent of language, capable of recording and accessing health care records, disease and symptom attributes, hospital admission notes and other relevant data. The technology is now available.

What are the advantages of this comprehensive medical record? To start with, a comprehensive medical record allows continuity of care for patients wherever they enter a dispersed and fragmented health care system. Doctors in remote areas have access to a complete catalogue of medical expertise and research. In emergency situations, this information can be vital and vastly improve the prognosis and treatment of a patient. The electronic record helps avoid errors, reduplication of procedures, and delays.

For the physician, a standardised architecture that integrates expert information and disease management guidelines reduces the need to refer patients to other specialists. Consultation with other physicians, who can have immediate access to parts of a medical record, becomes easier. Significant advantages also exist for medical research. The creation of a large amount of comprehensive medical data will generate information for disease research, health outcomes, and other factors that enhance medicine based on the best available evidence. For the patient, the result will be medical care that is increasingly based on insights derived from studying the experiences of many patients.

Few practising doctors have any training in how to record or store data. As a result, implementation plans must include a significant training element for the practitioners themselves.

Medical Networks in Practice.

Until this point, the Forum had discussed the implications of medical information networks and their existence in theory. As Mr. Simon Stone of IBM's Health Network Solutions explained, there are now numerous examples in North America and Britain of small-scale medical information networks that are fully functioning. Not incidentally, they are proving to be tremendously productive and cost-efficient. Three of his six examples are described here:

- **Pharmanet, British Columbia:** Pharmacare is the drug prescription management program of the province of British Columbia that connects 600 pharmacies and over 1,500 pharmacists. The network integrates 14 different pharmacy software packages and stores a patient's medical history and all current medications. Its purpose was limited to recording transactions on the premise that obtaining a more accurate picture of pharmaceutical transactions was the best way of detecting fraud. This system, which cost \$1.5 million (CDN) remarkably paid for itself in 6 months by uncovering widespread abuse. But the benefits also extended to patients. The program's director believes that the number of deaths directly attributed to adverse drug interactions has been reduced by 50 percent as a result of Pharmanet.
- **Salisbury NHS Trust, UK:** Salisbury is a modern National Health Service Trust hospital. Long before there were national initiatives on electronic messaging, hospital administrators recognised that they were wasting time and money bringing patients into the hospital for unnecessary tests, or consultations when test results were not ready. The hospital implemented a system using structured messages and a message centre linked to 200 users. Two of the major GP practice management systems take those messages directly into the patient record in the practice management system. The hospital found that it could significantly reduce the time between diagnosis and treatment simply by reducing transit time of data in a rural area. While not a patient medical record, this basic communication tool nonetheless gave all local general practitioners access to pathology and radiology results, discharge summaries, child health screening results, "good practice guidelines,» and the like.
- **Barnes-Jewish-Christian, St. Louis, Missouri:** The merger of these three hospitals in St. Louis created a very large institution that served 45 percent of the local market and employed more than 3,500 physicians. Each of these institutions had made considerable investment in hospital information with at least six different information systems. But it was not clear that any of the existing systems should be expanded to become the sole system under the new merger. Instead, they managed to protect their existing investments and rely on a system that integrated the data while storing it on a repository at the institution that owned it. The system can now provide current patient information at the point of care and eliminate duplication of service.

Because these systems are essentially local, they have avoided the problems that larger information systems face. For example, they use a set of common terms to describe the same procedures or observations, something that may not be true when a network attempts to integrate health care systems across regions or national boundaries. These examples further show that technology itself is a tool in building more team-oriented approaches to health care simply by making communication an easier process.

In British Columbia we see how these systems can actually save lives and provide a high degree of economic efficiency. Elsewhere, the networks reduce costs by providing more accurate data and, in some

cases, bringing true clinical value. But in most instances, these localised electronic networks do not represent the grand vision of a fully networked system described at the beginning of the Forum.

Yet that is no criticism. While there will always be calls for better evidence, more long-term studies, and more proof of the cost-effectiveness of information technology in health care, the examples offered by Mr. Stone suggest that incremental measures can have a significant, even transformative impact. Even experiments in electronic data interchange -- not a full electronic medical record -- have made a tremendous difference by providing clinicians with accurate data, eliminating the repetition of inputting data, and avoiding the distortions of subjective interpretations. By allowing physicians to see how information technology can improve their work and the care they provide, these first steps are critical building blocks in creating a constituency for more expanded medical information networks.

Electronic Medical Records in France.

Is it possible to implement advanced medical information systems on a broad or national scale? That is the goal of the French government. Mr. Jean-Michel Fay, Deputy Director for Information Systems at the French Ministry of Health, briefly outlined his government's agenda as it pertains to hospitals. Spurred by a national policy aimed at reducing costs inside the health care system, the French Ministry has embarked on an ambitious project to create a national medical information network for hospitals and providers and co-ordinate existing health information systems.

By 1998, the government hopes to establish an «extranet» that links 300,000 health care professionals across the country. Although more than 100 information networks already exist in France, most of them serve only the originating hospital. The Health Social Network (Reseau Santé-Social) will facilitate exchanges of administrative data between hospitals and regional authorities. It will also permit an independent practitioner far from a large hospital to gain information and advice at the cost of local phone call. Above all, the network will become a «federative mechanism,» bringing disparate information networks together through electronic directories and a messaging service. Within two or three years, French citizens will be issued a «Sesam-Vitale» electronic health information card, while health professionals will be issued a practitioners card that permit appropriate access to medical networks.

It is the government's belief that networks like the one now planned foster a co-operative approach to health care that will permit a better return on the investments already made on information technology within the health care system. In order to attract health professionals to join the system, the network offers a range of prices for varying degrees of service. Hospitals will be charged based on the number of work stations and physicians with access to the network.

Information Technology and the Pharmaceutical Industry.

As Mr. John Prichard of SmithKline Beecham explained, the changes underway in health care financing are having a direct impact on the work and strategy of pharmaceutical companies. Today across countries, an average of 10 percent of health care expenditures are directed toward pharmaceutical products. As the demand for greater efficiency and lower cost in health care grows, health care payors will be interested in more than merely the clinical results of new pharmaceutical products. They will want to look at the total social and economic impact of new products as a way of addressing opportunities for savings in the 90 percent of health care spent on non-pharmaceutical products and services. This will become increasingly important as economic benefit has to be demonstrated to health care payors in order to achieve timely product registration, and appropriate

pricing and reimbursement levels. The pharmaceutical value proposition will need to demonstrate value to payor as well as patient.

Increasingly we can expect some pharmaceutical companies to move beyond research and development into “disease management”.

Although disease management can be defined several different ways, from the pharmaceutical perspective, it means looking at the scope of health care procedures and seeking the optimal use of every element of medicine and care, not just prescription and over-the-counter drugs. But if disease management is to work, it ultimately needs information in electronic medical records and a standardisation of clinical data at a level of granularity that is consistent across countries and internationally. It also requires the presence of medical information networks to allow longitudinal patient records to be built up reflecting every contact between the patient and the health care system, and to allow that longitudinal record to be made available at the patient point of care.

Successful disease management will not only provide better long-term treatment for the patient, it will allow us to measure and evaluate the effect of various medical practices. For the pharmaceutical industry, it will have a direct influence on the prescribing pattern of physicians, for example, by generating evidence which demonstrates that use of a pharmaceutical product reduces the overall cost to the payor by avoiding expensive secondary or tertiary care. Other possibilities include identifying where cheaper generic products can be used in place of more expensive drugs -- with no patient impact -- to release funds which can then be deployed to provide therapy in areas of unmet medical need.

The creation of a system that would support disease management at this level is an immense undertaking. But as Mr. Prichard pointed out, it does not need a "big bang" process across the entire health care system. Comprehensive medical networks could be adapted gradually, establishing a system as a single sub-specialty to begin with. The goal, however, should be to make these networks an integral part of medical practice, not something a handful of practitioners can "add-on" to their daily routines.

The pharmaceutical industry's interest in how a medical information network could improve patient care is readily understandable. But we should not lose sight of the fact that information technology can also be enormously beneficial for the pharmaceutical regulatory process. Mr. Flavio Argentesi of the Joint Research Centre of the European Commission spoke to the Forum on the development of «EudraNet,» an intranet designed to meet the requirements of the pharmaceutical regulatory activity of the European Union. The goal of this system is to provide fast and reliable exchange of messages and documents that are related to regulatory and safety issues. Patients and providers are able to look up the characteristics of a drug and the system can provide quick reports of adverse reactions to pharmacological products. Establishing a network like this requires immense co-ordination of information systems scattered across Europe. The gradual, but successful development of this system reminds us that the challenges faced by medical information networks are not only conceptual and legal, but also technical.

Insurance Cards In Germany.

Undoubtedly the most successful experiment with electronic medical information has been in Germany where the «Versichertenkarte,» or insurance card had been distributed to 73 million people. Dr. Otfried P. Schaefer, considered to be the pioneer of this technology in Germany, discussed the role of the card and

its future implications. Introduced by federal law in 1992, the insurance card is the largest test of a chip card in health care ever undertaken.

The card, used strictly for administrative purposes, has a small amount of memory (256 bytes) and contains only eight items of information: (1) the name of the insurance group; (2) the insurance ID number; (3) the holder's name and title; (4) address; (5) date of birth; (6) insurance status; (7) ID number; (8) card expiry date. Developing the card and implementing it cost the German government DM 410 million, including the cost of outfitting doctors' and dentists' offices with card-reading machines.

The card has been fully accepted by patients and is routinely used now by hospitals and doctors' offices. Opposition in the medical profession has come mainly from primary care physicians who have discovered that the card has given their patients a new level of mobility and portability, allowing them to see more specialists directly without referrals.

The initial success of the card has prompted a host of imitators. In 1996, thirteen different proposals for electronic cards emerged for various parts of the health care system. These included a card for pharmaceutical prescriptions, dental treatment, patient history, and various small pilot projects. Numerous European countries have embarked on experiments with health-related cards.

For its part, the European Parliament has proposed a health passport to be issued by Member States in 1999 on a voluntary basis. Other innovations will be the use of health professional cards that will contain an electronic signature component. It will allow doctors to gain access to files, data banks and patient information (once consent is obtained).

The most regrettable fact about all these developments in electronic data cards is that none of them have any use outside their own discrete system. Yet the technology clearly exists to allow patients from one country to carry their insurance and even medical history with them to a hospital or physician in another country. If the electronic card is to move to the next stage and gain wider acceptance, some integration of these electronic systems will be necessary.

The Problem of Information Overflow.

Dr. Terje Johannessen of the University of Trondheim in Norway raised some of the practical problems facing physicians in a world driven by new medical information. The advancements in medical networks may create more efficient access to patient and general medical information. But now physicians must deal with a previously unknown volume of material that becomes useless when a clinician needs a quick reference during an examination of a patient. A complete medical record for a patient with a complex medical history could take up to 30 minutes to read.

The issue, in other words, is not simply easy access to medical information but an easier way of digesting the most pertinent information. Dr. Johannessen suggested two methods. The first is a «core medical record,» which would be a tightly edited and updated record of the most important facts in an individual medical history. The core medical record could be part of the complete medical file or be stored on an electronic health card. The other proposal is an «electronic clinical handbook,» intended to put the immense amount of data and new research and information into a more manageable form for the practising clinician. The goal would be to create a multimedia product continuously updated and supported by government that provides basic information about symptoms and signs; treatment and management; and patient information. Unlike the internet, where information is vast, undifferentiated,

and hard to locate, the clinical handbook would take advantage of electronic data systems to create a continually updated source book.

IV. Requirements for Wider Adoption

Until this point, the Forum had restricted its discussion to the scope and applications of medical information network technology. For the remainder of the proceedings, speakers shifted their focus to some of the difficult practical and policy challenges that every OECD nation must grapple with in order to create an information-networked health care system. This segment began with two views on regulatory reform.

Mr. Akira Kawamoto of the Trade Directorate of OECD began with an overview of the role of regulation and how it can be reformed to enhance the efficiency of a given market. Pointing to experience in other areas, such as the deregulation of the airline industry, he argued that competition can improve the quality of service while lowering its cost. In thinking about deregulating the health care market, one critical distinction must be made. It is both desirable and possible to dismantle economic regulations that restrict competition while retaining quality regulations. Indeed, in a more open, competitive market for health care services, there may be a need to enforce quality regulations even more strictly.

Information technology introduces an entirely new factor into the discussion of the deregulation of health care: the possibility of competition from abroad. Because, as the Forum participants had already discussed, a medical network makes possible consultation and real-time medical advice, the local monopoly on health care knowledge will break down. The result could be both the diffusion of new medical ideas and even drastic cost reductions.

To understand what role regulatory barriers play in inhibiting or promoting the advancement of information technology in health care, Mr. Kawamoto posed four questions that might be asked of government policy makers:

- Can patients go to foreign countries to receive treatment, or can foreign patients come to your country to do so?
- Can hospitals be established by foreign firms or individuals?
- Can health care services be provided from foreign countries through non-physical contacts?
- Can foreign doctors, nurses, or other medical personnel come to your country to practice medical treatment?

Governments that persist in maintaining domestic regulations that prevent foreign health care professionals, services, or institutions from operating within their boundaries will be less successful in blocking the effects of information technology. Invariably, information technology will succeed in circumventing national regulations, and governments will be forced to adapt.

The lesson for policy makers is to view the possibilities of competition created by information technology as an opportunity. Health and technology officials should be encouraged to work with trade or competition policy officials to reform regulations so they respond to the opportunities of health information networks.

Creating a regulatory framework that extends over a number of national boundaries is not a small undertaking. Dr. Denis Mrejen, the convenor of the health care subgroup of the European Information Technology Industrial Round Table, outlined several problems faced by the industry as it attempts to integrate information technology health care:

- decision-making in health care is highly fragmented;
- tariffs for public networks remain too high;
- there is no standard interface for capturing diagnostic and therapeutic data or for structuring the electronic medical record;
- legal issues remain unclear, especially as they relate to the protection of confidential and person related data.

Without a combination of political and market pressure, it would be difficult to co-ordinate the efforts of various industries. Co-ordination problems are directly linked to the absence of common coding numbers and protocols for collecting medical data. Similarly, there are no uniform, international standards for the transmission of information and how its security can be insured.

Overcoming these problems encountered by the European Information Technology Industrial Round Table are central to the advancement of medical information network technology. Issues of co-ordination, standardisation, and security beg the critical questions: What role should be played by the associations of those who use medical information networks? What is the respective role of the industry and the public institutions for establishing standards? Who should set rules for security -- and how? These questions would become the chief points of discussion for the remainder of the Forum.

V. Standardisation.

Both the United States and the European Union have recently undertaken steps to standardise the use of some medical information technology. The Forum heard presentations on these experiences, which demonstrated two very different approaches.

Recent Experience in the United States.

In the United States, the growth of electronic networks for health insurance claims processing has grown considerably and is credited with helping reduce the health care expenditure inflation rate. According to Dr. Michael Fitzmaurice, the Director of the Centre for Information Technology in the U.S Department of Health and Human Services, there are now more than 400 different electronic claims systems operating in the United States, but little standardisation among them. It is in situations like this, Fitzmaurice suggested, that industry turns to government for the things it cannot do itself, and standardisation appears to be one of them.

In 1996, the U.S. Congress, at the urging of health payors, plans, and providers, passed legislation that created a legal process for the adaptation of health care data standards and the rules for implementing them. Ten types of transactions are to be governed by these new laws, including claims information, premium payments, referral authorisation, and the co-ordination of benefits. In addition, the Secretary of Health and Human Services (HHS) must adopt standards for electronic identifiers, code sets, security measures, and the use of electronic signatures. Once in place, these rules will apply to all health plans in the United States, health providers, and the health clearinghouses that typically transmit claims from the

claim processing company to the ultimate payor. These standards, to be adopted by 1998 and implemented by industry in 2000, will require payors to accept standardised electronic transactions or face a \$100 per violation fine (to a maximum of \$25,000).

Most notable about this process is that the law explicitly directs the Secretary to seek out industry consultation to formulate these standardisation rules. According to Dr. Fitzmaurice, the goal is to have full industry acceptance before the rules are promulgated. If successful, it could be a model of government-industry collaboration on medical information networks. It will also likely prove a source of considerable cost reductions, as physicians find an easy-to-use, uniform claims system that saves them money.

As for privacy issues relating to the transmission of this data, Congress has reserved until 1999 the right to pass new privacy legislation. If a new law is not passed, the Secretary's privacy regulations can go into effect six months later.

There is now persuasive evidence that this type of *federal* standardisation is more valuable than local, community networks that have been attempted. In one case the Hartford Foundation, a local philanthropy, invested several million dollars to create community health information management systems. The plans brought together business, public health organisations, physicians, vendors, and network operators in six different communities. Yet these plans failed to achieve their goals. They were deterred by the lack of standards, the reluctance of business to share information with potential competitors, and the absence of any synergy capable of creating something bigger than the sum of the component parts. The communities themselves provided no funding and, as a result, played no role. Overall, the projects helped to generate numerous electronic transactions of health care information from one party to another, but no overarching network with uniform standards. The experiment provided more evidence that a national system, with standards and uniform applications was necessary.

Does recent experience in the United States have any application for other OECD nations? U.S. payment methods are based largely on private insurance claims, as opposed to a national health insurance system, so here international applications are limited. But many international efforts are already underway to identify those areas where common standards could be developed, particularly when it comes to protecting personal information, the management and structure of data, ownership and legal accountability issues, and the use of the network itself.

Recent Experience in Europe

Mr. Norbert Lipszyc provided the Forum with a European perspective on some of the same standardisation issues, based on his work with the Comité Européen de Normalisation's Technical Committee 251 (TC251), which deals with health care information and networks. As he explained, the original focus of the group, which began meeting in 1991, was very different from the standardisation project now underway by the U.S. government. Claim processing across borders was considered a minor issue since the European nations all have some form of national health insurance. Although there was an interest in patient care data, it was thought that attempting to standardise this data was too ambitious a project.

Representatives to the work groups of TC251 worked over several years in seven different work groups and 16 project teams. Representatives of the software industry had a strong interest in making interoperability a first priority because they wanted to advance software solutions without having to

replace the very software systems they were still marketing. By contrast, the representatives of the hospitals wanted interchangeability to be able to buy new solutions from any vendor and simply "plug it in" into their existing systems.

From 1991 to 1997, the Commission produced 48 different European health care information standards for areas ranging from messages, to security, to data architecture and models. Interestingly, during the same period, a parallel working group began developing standards for the use of patient health machine-readable cards in order to remain up-to-date and compatible with similar work in other fields. This year, the original group has been re-organised, focusing on four main issues: information models (including definitions for an electronic medical record); common medical knowledge bases; security, safety, and quality related to medical information technology; and finally the interoperability of technology, allowing one system in one region or country to adapt to another's.

Are any of these European efforts on standardisation successful at this stage? On the one hand, the quality of the work and the standards established thus far has been very high. But on the other hand, the work has had little impact on the market place. No product or hospital information system has been created in the last few years that can claim to conform to the new European standards. (The one exception would seem to be the planned French patient health cards, discussed earlier in the Forum.)

That is not to say that the efforts thus far were useless. If anything, they suffered from being too ambitious at the outset, hoping to accomplish goals (such as the complete interoperability of medical software) before the technology was fully developed. The technology, however, has caught up. The fact that standards for medical information technology are already in place suggest that new products will emerge in the next few years that will conform to these standards.

The discussion that followed these two presentations on standardisation forced participants to focus more intently on what we mean by standards in medical information technology -- and what advantages we can expect from them. Some expressed concern that the move to impose standards on new products will only raise prices. Hospitals, which could benefit most from advanced, uniform medical software packages, are unlikely to be able to afford such high-priced products, making the availability of uniform network technology useless to them. Others, however, argued that standardisation itself is a necessary precondition of a broad market for new information technology products. Products that allow medical practitioners or hospitals to take advantage of new software -- regardless of where it is manufactured -- create a previously non-existent market, which eventually will cause prices to drop. Standardisation, in other words, allows a «critical mass» of potential users to develop.

The question policy makers and industry face is whether, in the pursuit of standardisation, government imposes new regulations that merely induce higher prices on the entire system. To avoid that, standardisation must be seen as a competitive mechanism. A single country, operating in isolation, developing its own standards for medical technology, does little to advance the cause of cross-border competition. The lesson we learn from recent U.S. experience is that industry was willing to urge the government to create standards in order for competition in information technology provision to thrive. What governments must realise is that by providing the standards, new products will be able to generate new information about the health care system and the way patients are treated. That information, in turn, becomes a powerful cost-saving device.

Finally, the discussion on standardisation yielded one other general agreement. Standardisation in medical systems must not mean government dictates on patient care and treatment. Instead, standards for sharing information should allow physicians to refer quickly to the best-evidence when treating a

particular condition. But the standards themselves should not create «standardised» treatment. One Forum participant, representing a U.S. health provider company, argued that the value of treatment standards was to eliminate the bottom 10 percent of the practice while giving other physicians an easy yard stick to measure their own improvement.

VI. Protection of Privacy and Security

In some respects, it is surprising that concerns about the privacy of medical records should seem a necessary part of any discussion on information technology and health care. After all, in today's world, the millions of paper records containing personal medical information often have the barest security protections. Elemental security devices such as paper shredders or limited-access filing cabinets are still rare in most clinician offices.

That said, it is undeniable that the world of electronic transmissions of medical data over the internet or private intranets has opened an entirely new set of security concerns. Very recently the United States had a vivid demonstration of how fragile existing protections can be for private data. The Social Security Administration established a web site on the internet that allowed anyone to access the lifetime earnings data of any individual by entering only a social security number and mother's maiden name. In the face of enormous public protest the system was quickly withdrawn and redesigned.

These points were raised in a paper submitted to the Forum by Mr. William Poulos of the EDS Corporation and in the discussion led by his colleague Dr. Faye Baggiano. Poulos argued that we fail to distinguish between «security» and «privacy,» often using them interchangeably. In fact, security is just the means to protect privacy. What security protocols we choose will often be determined by what type of privacy we seek. Of course, the easiest way to assure total privacy of medical data is to deny any access to it. This obvious point reminds us that the challenge in formulating security policy is determining who shall have access to data and for what use.

In most instances, creating a security policy is not a major technical challenge. Despite a few highly-publicised stories about the exploits of computer hackers, most violations of private medical information do not occur as a result of a technical weakness. Instead the problem occurs when there has been a violation of confidence, or when someone with access to medical records shares them with someone who does not. The only remedy in those cases is a strong legal system that will enforce penalties and deter misuse.

Because legal penalties are viewed as an easily constructed barrier against the misuse of private medical information, the whole issue of privacy and security is often deemed a local one, subject to local legislation. But that no longer remains true once data is transferred across borders. In addition, there remain a number of related questions about the handling and use of medical information that should be addressed on a much broader scale. To begin with, a patient's consent to give others access to his or her medical record would seem to be a basic principle. Winning that consent will require that a doctor inform a patient about who else might have access to the record, whether it be consulting physicians or researchers to an anonymous epidemiological study.

A second related principle that needs clarification is the ownership of a medical record. In Germany, the very limited information on a government-issued insurance card is still owned by the individual and cannot be accessed without consent. But in Britain's National Health Service, it is far less clear who

owns millions of individual medical records. More complications ensue when dealing with genetic information, or even psychiatric or HIV-related information. If medical information networks will permit greater transmission of data across state and national boundaries, some international protocol may need to be established to see that these categories of sensitive health information are dealt with carefully.

In the course of this discussion, it became clear that the way in which private medical data is used matters greatly to patients. Patients, many argued, do not mind if their private medical data is used to support research or long-term health care studies. They are, however, far more resistant to the use of such data for commercial purposes. This is an important distinction when thinking about the consequences of overly strict security policies on health care advancements. A recent European Union directive on data protection may have a damaging consequence for pharmaceutical clinical trials, in which identifiable patient data, studied over a long-term, is indispensable. Similarly, it is impossible to conceive of effective disease management without the routine use of aggregated medical data. Security policies that inhibit this type of use of medical data represent a setback for medical information networks. The best solution is undoubtedly to return to the issues of patient consent, ownership, and the clearly stated intended use of the data as the guide for future security and privacy policy.

VII. Financing.

All medical information networks ultimately feel the impact of financing questions. Who pays? Where does the money come from? Can it be co-ordinated? Yet for decades in the United States, as Mr. Jacob Getson of AETNA U.S Healthcare, the largest managed care health provider, explained, payors rarely focused on how the money was used in health care. There were no incentives to take advantage of technology that might improve health incomes and, thereby, reduce overall costs. Because most health care in the United States was fee-for-service, hospitals had little interest in major investments in cost-reducing technologies and physicians had no incentive to collect data that would enhance preventive care.

The rise of managed care changed much of that. It also created a new role for information technology as a driver of quality outcomes and lower costs. Successful managed care depends on measurement and as a result managed care created opportunities for disease management and financial incentives for physicians to alter behaviour. According to Mr. Getson's estimate, 40 cents of every dollar in the old U.S. health care system represented some form of waste that could be redirected. His company believes that by rearranging the incentives, health care suddenly has lots of money to spend on better quality care and new technology. At his company, the collection of patient and physician data becomes a cost-saving tool, whether they are issuing «report cards» on their doctors or paying bonuses to physicians who are able to retain their patients (rather than have them visit a new doctor each time).

Mr. Getson argued that the system he described included the goal of enhancing the choices patients have, creating what Dr. Jean-Claude Healy of the Health Telematics division of the European Commission called «citizen-centred care.» In this new paradigm, market incentives should be established to create more information for a patient to choose the type of health care he or she seeks. Dr. Healy suggested fostering a health care telematics industry that operated not unlike today's pharmaceutical companies that constantly research and bring new health care products to the market. Through a national or international

accreditation process, companies would effectively be licensed to develop mass-market, on-line, multimedia, or interactive products for anyone in the health care system.

This step would require a more radical shift in medical information technology policy. Participating countries would be urged to pursue deregulation of the communications so that industries -- whether they be pharmaceutical companies, publishers, or TV operators -- could establish new telematic products. The result would be an entirely new paradigm for health care and information technology.

Government's role in this process, highlighted by Mr. Guy Rossignol of the French Ministry of Health, would include creating a favourable legislative context and generating public-private partnerships. Where new technologies, such as telemedicine, are concerned, the traditional regulatory and co-ordinating role of government agencies is increasingly giving way to the initiation of public-private partnerships. For example, the «Ten-Telemed» project linking 23 European hospitals with telemedicine services worldwide was initially launched by the French Ministry of Health, but is now managed by industry.

Conclusions. In his summary, the Rapporteur, Mr. Daniel Casse, noted the broad scope of the issues that fall under the umbrella of medical information network technology. As expected with such a large range of issues, many conflicting views on policy matters were heard. But on some basic points about the growing centrality of medical information networks there is no disagreement:

- Medical information technology is no longer a support tool of health care, but an intrinsic part of health care management and delivery.
- The use of medical information networks represents a major opportunity for reducing costs and improving the quality of care.
- Habituating hospitals and physicians to the proper use of information technology is one of the most critical steps in expanding information-driven health care.
- The rise of the Internet and other methods of electronically transmitting data have dramatically changed the ability of physicians and hospitals to consult with one another, take advantage of recent research, and evaluate health outcomes.
- Data collection has become a necessary part of treating patients and managing disease.
- The inability of countless private and public information networks to communicate with one another represents a serious obstacle to achieving all the benefits potentially offered by medical information technology.
- The development of technical and procedural standards -- both national and international -- is a pre-condition for advancing medical information technology.
- Both industry and government need to clarify the proper use of private medical data, focusing on issues of patient consent, transfer of information, secondary use, and safeguards to prevent inappropriate use.
- To take advantage of medical advances throughout the world, serious efforts should be made to adapt regulatory barriers and legal restrictions to promote the free movement of health care products, information, and services.

Because the ultimate success of medical information technology depends on efforts by both government and industry, the OECD can play a critical role in bringing focus and attention to these issues. By using its analytic and fact-gathering capabilities, it could provide a comprehensive study of health-related information technology in the member nations. Seeking new opportunities to co-ordinate and apply that technology should remain a priority of all member states.

Selected Quotations from the Proceedings of the Forum on Medical Information Networks and Technologies

«In the United States alone, health care accounts for nearly a trillion dollars in yearly expenditures, yet our system operates without a system-wide framework for defining, measuring, and or ensuring quality. I wonder if any other industry could survive in such an environment.»

-- David Bryan

«The most difficult part of advancing telemedicine is disseminating information about it and then winning acceptance of it.»

-- Tore Schersten

«Doctors can be very intelligent, but they can also have very poor memories. The Electronic Medical Record is not intended to replace the doctor, but instead to combine the memory of all medical school education with the full memory of a patient's medical history.»

--Alain Maskens

«There are great gains to be made from quite simple implementation [of medical information networks]. If we let the grand vision obscure the reality of what is possible, we will lose great opportunities.»

--Simon Stone

«Health care is a pick-pocket industry. There is no new money in health care. Government is going to have to find ways to reward people who bring new products to market or remove inefficiencies by taking money from somewhere else in the system.»

-- John Prichard

«The rise of the internet has erased the meaning of distance and national borders as far as information is concerned.»

-- Akira Kawamoto

«Establishing a European intranet meant co-ordinating email for 35 different systems.»

-- Dr. Flavio Argentesi,

«No national card system will last without respecting international standards.»

-- Dr. Otfried P. Schaefer

«A system that makes it possible to wire information from one institution to another will have an associated risk of creating chaos -- the amount of incoming data may be overwhelming....Today I struggle to keep an overview of my own patients with a medical record that I have edited. But tomorrow, when I have easy access to all the information from others, there is a risk that I will drown in data.»

-- Terje Johannessen

«[In health care discussions,] the rhetoric is high, with lots of talk about global issues, prevention, wellness, and quality, but there is virtually no payment that rewards these things.»

-- Jake Gedson

**BIAC Business-Government Forum on Medical Information Networks and Technologies
Paris, 17-18 September 1998**

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