From Punched Cards to Computerized Patient Records: A Personal Journey

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Summary

Objectives: This paper presents the early history of the development of CPR in Sweden, the importance of international cooperation and standardisation and how this cooperation has been facilitated by IMIA, the European Union and the standards organisations. It ends with the lessons learned after 35 years of experience put together by the Swedish Institute for Health Services Development, SPRI, in a 5 year project initiated by the Swedish Government and with participation of most health care providers in the country.

Methods: Starting with the first attempts to use punched cards to store and use patient information for clinical use the author describes his troublesome and difficult road to a Computerized Patient Record that could be used both for the work with the patient and as a tool to follow up both the diagnostic and therapeutic processes and for clinical research.

Results: The most important results of the efforts to develop a computerized patient record in Sweden are published in many reports, among them three SPRI reports published in the late 1990s, and they are: Standardized information architecture, a common terminology, rules for communication, security and safety, electronic addresses to all units and users and an agreed upon patient and user identification.

Conclusions: The future CPR must be problem oriented, capable of only adding new information instead of repeating already-known data and be available in real time regardless of geographic location. It must be possible to present the information in the CPR as "views" where the healthcare provider has stated in advance the information needed for his patients. There can be a number of "views" for different occasions.

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Keywords

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Information Technology in Health Care

The entry of information technology in health care has been slow, due in part to the conservatism that has always been part of health care, and in part to the immense complexity of health care, both in working routines and organisation. Until now, it has not been feasible to create overall and effective computer support for multi-faceted and varying activities such as health care. To understand why this has been the case and why this will now change radically, it is necessary to understand what information technology means, including what it is, how it is developed, and where it is headed. Without this basic understanding of the new concepts and the new patterns of thought that govern and distinguish information technology today, discussions about it inevitably end in confusion.

In the years since I began my career in medicine and medical informatics, information technology has evolved. It is no longer about computers; it is about networking knowledge communities. Health care professionals want computerized patient records so they can access them when and where they want, without having to search physically for paper-based records. Yet technologists and engineers still find it difficult to understand health care. Because there is little understanding of the many possible changes in working routines that are critical to realizing the benefits of information technology, the marketplace to date has focused on creating "authentic-looking" computerized records that replicate paper-based patient records and the ingrained working routines they represent.

Medical informatics has, for me, always been focused on the documentation necessary for care, more specifically, on making it easy for the health care professional to enter and to retrieve essential information. This is not a simple task. Rules and practices as to how documentation should be done differ widely, between and within countries and hospitals. In many countries, laws mandate documentation and may even specify such details as who is responsible for that documentation, how the documentation can be made accessible to other members of the care team, whether the patient has access to the documentation, and what structure is used to present the information.

In order to document care, certain prerequisites must be met. A number of subsystems must be developed that to "feed" the patient record with relevant information from the medical services that produce between 60 to 80 percent of the information in an ordinary patient record. Technical problems such as safety, security, user interface, communication, terminology, and standardized structure/architecture must be solved, and challenges in areas such as education and cooperation must be addressed. Combined, these make the development of computerized patient records extremely difficult.

Personal Experience

Starting Out

In 1962, as a young physician in the Department of Ophthalmology at the Karolinska University Hospital (KS) in Stockholm, I first came in contact with one of the early attempts to store medical information in a digital format. At KS, I met Dr. Paul Hall, who had been struggling since the late 1950s to use punched cards to store patent information and create a patient record. I saw a possibility to do something similar. By 1963, I had developed a system that stored the information needed in tests of new eye drops on three punched cards.

When I began, the hospital had only a key punch machine and a sorter. To retrieve the information, it was necessary to sort the cards many times. By the time I had test results on 80 patients, the sorting could no longer be completed in one night. The technology to do the work was not there. Then the hospital got its first computer, an IBM 1401 with 4 K memory and two magnetic tape drives. Once the material was stored on tape, the process to get the necessary information took only a few hours [1]. The programming language known as Auto coder allowed me to do all the programming myself.

The number of patients for whom I had records grew. After a year, the data could no longer be updated in a single night. Then, as before, new technology saved my project. In 1967, the hospital got an IBM 360/40, solving our capacity problems at that time. In addition, the hospital installed an IBM 1800 data acquisition and control system, connecting it online with laboratory instruments that collected signals from a number of different instruments. In both instances, medicine pushed for the development of new technology and was served by it. Today, medicine continues in this dual role [2].

In 1971, I was appointed head of a new department of medical informatics at the Stockholm County Health Care Administration. It was the central organization for all the health care resources for the 1.6 million inhabitants in the County, which included 64 hospitals with 24,000 beds and over 100 primary care centres [3]. Our main goal was to develop and implement a computerized patient record (CPR) for the whole organisation. To do so, a plan was put in place to achieve three priorities as the groundwork for the CPR:

1. Have a patient administrative system up and running at all the hospitals in 1974 [4]
2. Computerize all laboratories with local minicomputers
3. Implement an administrative system for the primary care centres.

When all these systems were in place early in the 1980s, the time had come for the CPR. Various systems were implemented, but none was widely accepted. Some were developed by a physician and rejected by other physicians. In 1984, the first commercial system, translated and slightly modified version of the Costar system, was installed at one of the primary care centres. General acceptance of the use of the CPR in Sweden did not come until the mid 1990s.

Early International Work

In May 1966, I participated for the first time in an International Congress in the field, held in Elsinore, Denmark. Conferees came not only from Scandinavia, but from all over the world. The persons who presented papers came from many countries. Their numbers, shown in Table 1, reflected the countries that started and made the early developments in medical informatics [5]. Their names are recognizable as early pioneers in the field, a few are still active today, 40 years later.

In the 1960s and 1970s, I became increasingly involved in work begun under the auspices of the International Federation of Information Processing (IFIP). Founded in January 1960 with 15 member countries (now 58), IFIP is organised in Technical Committees (TCs) which in turn can have Working Groups (WGs) [6]. In 1967, TC4, Medical Information Processing, was started with Francois Gremy as the first chairman; it had four WGs. In 1974, TC4 held its first own separate congress in conjunction with IFIP's triennial World Congress in Stockholm, where the question of a more independent position to IFIP was discussed. In 1977, at the next IFIP Congress in Toronto, TC4 was accepted as a Special Interest Group, but the pressure for independence resulted in a decision in IFIP to accept the International Medical Informatics Association (IMIA) as an independent organisation. At a meeting in Berlin in 1979, David Shires (Canada) was elected President, and I was named Vice President and President Elect.

The International Medical Informatics Association (IMIA)

In the years following its official birth date of January 1, 1980, IMIA assumed the role of a bridge organization, overcoming geographic and professional boundaries as it moved to define and advance the field of medical informatics. Every three years, IMIA holds an International Congress, known as MedInfo, drawing 900 to over 2000 participants. Its proceedings have been cited in the medical informatics literature. Since 1992, IMIA has also published a Yearbook of Medical Informatics distrib-

Table 1 Countries Represented by Presenters at the 1966 International Congress in Elsinore, Denmark

Country	Presenters of Papers
United States of America (21)	DAB Lindberg, H Warner, J Macy, H Well, H Pipberger, L Stark, C Flagle, L Lusted, J Baruch, G Z Williams, E Cotlove, J Korein, LJ Tick, SI Allen, PJ Budd, W Kirkham, J Bigelow, C Caceres, M Weil, W Clark, and O Barnett
France (7)	JC Pagès, F Grémy, Grening, JB Cornish, J Guigan, JF Davies, and A Rémond
Great Britain (3)	H Yellowlees, ED Acheson, and AE Bennet
The Netherlands (2)	J van de Geijn and DH Bekkering
Italy (2)	A Masturzo and F Serbanescu
Germany (1)	G Wagner
Poland (1)	J Wartak
Japan (1)	K Takahashi
Puerto Rico (1)	A Lassus
Norway (1)	T Hauen
Sweden (6)	G Jungner, P Hall, O Arvedson, I Petersén, W Schneider and T Dalenius
Denmark (9)	A Tybjaerg Hansen, A Marchmann, E Dessau, E Sandoe, M Jorgensen, J Mosbech, P. Dragsted, E Kaiser and C Guld

uted by medical informatics associations around the world. Each Yearbook includes invited papers on timely topics and describes IMIA activities, with reports from its member countries, WGs, and its five regional groups.

The WGs have been the lifeblood of IMIA. Together with the WGs in TC 4, they have played an important role in the development and importance of the field. During the 1970s and 1980s, more than 25 books of proceedings were published from working conferences organized by WGs. Although a few volumes were not indexed, making them hard to find, all of the WGs have made a significant contribution by making it possible for people to meet and agree on how difficult problems could be solved, and by disseminating their conclusions and recommendations to a much broader audience. As an officer of IMIA, I tracked the activities of all the WGs. Several held special interest for me personally.

One of these contributed to the development of the CPR. As WG 10 Hospital Information Systems, it published the proceedings from one of its working conferences, held in 1978. This volume, "Towards New Hospital Information Systems," contains what is close to a complete history of early developments [7]. Today this same WG continues its work under a new name, WG 10 Health Information Systems.

Another group, WG 4 Data Protection in Health Information Systems, has made invaluable contributions. Proceedings from a working conference organised in 1976, "Realization of Data Protection in Health Information Systems," identified the problems facing medical informatics in this area [8]. Solutions were harder to find, and there are still disagreements as to how solve a few of the problems identified then.

Nursing Informatics started as a WG with a Congress in London and Harrogate in 1982. The proceedings from 1982 were titled "The Impact of Computers on Nursing: An International Review" and included papers from all over the world [9]. This WG was later granted the status of a Special Interest Group, the only such group in IMIA. Its history is well documented in "International Nursing Informatics: A History of the First Forty Years." [10].

The first of IMIA's regional groups to be established, the European Federation for Medical Informatics was inaugurated in 1976 in Copenhagen by the initiative of Dr. Mogens Jorgensen.

In 1995, Marion Ball presented a booklet "Bridging to New Words" that described the landmarks during her presidency and included a section entitled "The Presidents Reflect," where her predecessors summarized their memories and accomplishments from their terms of office in IMIA and IFIP TC4, as summarized below [11].

Francois Grémy established TC4 and recruited the first generation of members from the medical and health care community. Intellectually as well as organisationally, he was the true predecessor of IMIA. Jan Roukens was deeply involved with the transition from IFIP-TC4 to IMIA. "Increasingly, medical computing became a field where the computer and medical worlds met, and IMIA was established to meet the needs of professionals from both. In retrospect, it seems quite incredible that all of this was realized in a period of a little more than 2 years. IMIA succeeded by giving its members a platform, an intellectual framework, for discussion. Its domain of discourse is scientific and essentially liberal."

David B. Shires reached agreements with the regional group for Central and South America and the People's Republic of China making them active participating members of IMIA. He saw IMIA as a family, within which "the USSR

Table 2 Facts about IMIA

IFIP TC 4 Chairmen	
Francois Grémy, France	1967 - 1974
Jan Roukens, The Netherlands	1974 - 1980
IMIA Presidents	
David Shires, Canada	1980 - 1983
Hans E.Peterson, Sweden	1983 - 1986
Shigekoto Kaihara	1986 - 1989
Jos L. Willems, Belgium	1989 - 1992
Marion J. Ball United States	1992 - 1995
Otto Rienhoff, Germany	1995 - 1998
Jan H. van Bemmel, The Netherlands	1998 - 2001
K. C. Lun, Singapore	2001 - 2004
Nancy M. Lorenzi, United States	2004 - 2007

Medinfo's	
1974	Stockholm, Sweden
1977	Toronto, Canada
1980	Tokyo, Japan
1983	Amsterdam, The Netherlands
1986	Washington, United States
1989	Beijing/Singapore
1992	Geneva, Switzerland
1995	Vancouver, Canada
1998	Seoul, South Korea
2001	London, Great Britain
2004	San Francisco, United States

and Eastern bloc countries could indulge in animated and mutually productive discussions with their western counterparts, with respecting the other's political differences."

I related how I, during my presidency, had to handle a financial crisis, when "there was no money." The financial blow came when IMIA closed its permanent secretariat in Amsterdam and its small remaining treasury vanished. "It was very little time for accomplishments and achievements. The goal was to survive. I see IMIA as an international body free from political and governmental influence. In this body we have to cooperate also with industry and get a mutual understanding that cooperation is the only way out."

Shigekoto Kaihara was confronted with the problem that the People's Republic of China had been accepted for Medinfo but the events in Tienanmen Square made many possible participants hesitant to go to China. The final resolution was to hold a two-part Medinfo. Medinfo Beijing rewarded the work and the eagerness of its organising committee, and Dr K C Lun applied his ability to arranging Medinfo Singapore. Dr Kaihara stated: "There is no comparable international organisation in the field of medical informatics."

Jos L. Willems stated that "The major challenge of the presidency is to keep IMIA's activities going. The major task is to stimulate people. The organisation is up to now entirely run by volunteers. IMIA needs a paid executive secretary and secretariat if the organisation wants to grow." Under his presidency, the first IMIA Yearbook came out and IMIA received official recognition as Non-Governmental Organization (NGO) to the World Health Organization (WHO).

Marion J. Ball oversaw the creation of a new IMIA, designed to be a bridge organisation and to move theory into practice. Its governance was distributed to five new Vice Presidents to give the Board added vigour and vitality to pursue IMIA's mission. According to Ball, "IMIA's future depends upon becoming a professionally-run organization, and must liaison with other sectors and offer value to its member-ship, including its newly created category of institutional members." Under her presidency the Asia Pacific Association for Medical Informatics (APAMI) held its inaugural meeting in November 1994 in Singapore.

Other International Activities

In Europe, other organisations in addition to IMIA play key roles in medical informatics. The European Commission's research and development programs in medical informatics have produced important and impressive results. More importantly, the Commission has fostered cooperation between people from different countries, and contributed to the understanding of how important cooperation is.

Activities in the area of standardization in the 1990s bear testimony to this kind of cooperation. To address the critical area of standards development, for example, George de Moor (Belgium) asked a number of people from different countries in Europe to stay after a meeting in Brussels in 1990 to discuss starting a new TC within the Comité Européen de Normalisation (CEN). We agreed that the TC was a good idea and took the concept to their national standards institutes for approval. (I got the acceptance from Swedish Standards Institute.) With funding from the European Commission during its first few years, the CEN TC made a good start, and a number of standards were accepted before problems slowed down the TC's work. Toward the end of the 1990s, the international standards community discussed starting a TC under the International Standards Organization (ISO); this group is now active and working. This collaboration is critical, because without international standards it is

impossible to agree how to communicate, which terminology to use, how to ensure patient privacy, and how to protect the data.

Lessons Learned

My vision is to see how the future multi-professional, multi-media, organization-independent electronic patient record in which only new information is added instead of repeating the already known information should look like and from which the user can decide what information is needed for the next decision and how this information should be presented.[12] This demands interoperability across professions, organizations, and media; and it demands robust computerized patient records.

Interoperability

Health data management requires interoperability of all applications within a hospital and across groups of hospitals and primary care centres that work together or are in the same region. As of yet, no single integration strategy achieves this goal, and the three most common approaches have not succeeded, despite many attempts:

- The *single supplier solution* gives the entire organisation a common data base with no duplicate data elements. Yet no one user gets exactly what he needs, and everyone within the organization has to compromise. This type of system has proved unsuitable for groups and regions because of high cost and long lead times.
- Although multi-vendor, "best of breed" systems are easier to adapt and grow, and the investment is spread over a longer period, they present data integration problems that require complicated architectural fixes. The traditional method of linking systems through point-to-point proprietary interfaces can be very costly. Interfaces may need to be amended if changes are made in the connected systems, potentially costing more than the individual applications. Attempts to overcome these problems by using generic interfacing tools, the so-called "interface engines," have had limited success.
- In 1997, the Organization for Economic Co-operation and Development (OECD) recommended *"open" modular solutions based on standards* [13]. This approach calls upon health care to adopt common architectures and interfaces based on "public" standards, making specific applications or software products and linkages available to both users and vendors. It is important to distinguish clearly between the "quasi openness" vendors claim for their proprietary systems and "real openness" of systems based on public standards.

Computerized Patient Records

Interoperability is critical because a patient record consists of all the documents that are created by different care providers or are received in connection with the care of a patient. Usually there are many care providers involved in taking care of the patient. It is therefore a need to take part of the information and to document the findings. Traditionally, the patient record was a tool for documenting of actions already taken; today, it is used more and more as a planning instrument to steer and follow up on the entire care process.

When patient records become electronic, the traditional structure ceases to exist. The screen can present the record in the traditional way and also in a customized format desired by the care provider. Yet, the potential of the CPR far exceeds its use in carrying out the processes within the framework of diagnostics, treatment, prognosis, and follow up.

It has long been obvious that CPRs have real value for health care principals and providers, and that part of this lies in the ability to transfer patient data where they are needed. This is the problem that the new ways of communication tries to solve. For the health care provider, patient data must be presented as one computerized record, even if the data may be scattered across a hospital, region, or country. Typically, the health care provider requires only a subset of the data about the patient at each visit or consultation. By means of distributed object technology, these requirements can now be met.

The new CPR is bold in the sense that the original data can be presented or formatted in different ways in different places, although the data have a common format when they are retrieved, from different databases. Thus, distributed patient data are made available through references, such as hypertext links, and are accessed as needed by the health care provider. Object technology allows the user to retrieve parts of the records (such as single patient record items or patient record item complexes) in preference to the entire patient record, the data flow across the network are minimized.

Object-oriented development methodology is one of the most important advances in information technology. It divides tasks into independent parts known as "objects" and has these perform their tasks "without anybody watching." The end result is a completely new view of how organisations work, as well as a revolution in the development of large complex software systems. IT increasingly governs how activities are conducted and organized. New technology breeds new forms of

work, which in turn breed new organizational forms.

In networked systems, distributed transaction management and reference counting preserve and protect the data from contamination. In this way, full access to and updating of patient records can be given to many different health care providers, simultaneously or at different times, without record items being overwritten or lost. Many of these functions and procedures are already specified. Although this requires that the database be continuously connected to all parts of the network for full data integrity to be preserved, large bandwidth (network speed) is not needed unless large amounts of imaging or video data are to be transmitted. Of course, an extensive data security infrastructure is needed to prevent patient data from getting into the wrong hands. The difference between technological development in general and information technology (IT) in particular is that IT manages information and thus knowledge. To refer to IT as computer support in health care is no any longer true. IT is not about computers but about globally interlinked collaborative information technology, which creates a networking knowledge society through the application of the Internet and Intranet [14].

Summary of Practical Results

Today, IT in health care is guided by the lessons learned over 40 years of development. These can be summarized in four categories:

Purpose
- Support high quality health care with high quality information processing
- Produce administrative statistics about production, quality of care and cost
- Allow individual clinical follow-up and research

User requirements:
- Support daily work with the patients and process-oriented health care delivery
- Support communication possibilities both inside and outside the unit
- Have a common information structure/architecture and use a common terminology

Goals
- Build small local modules that can be used in different applications, have a standard interface, and are easy to replace
- Build modules that can communicate within the local system but also be a part of the "total" system

Prerequisites
- Standardized overall information structure/architecture
- Agreed upon terminology
- Rules for communication, security, and safety
- Agreed upon patient identification
- Electronic addresses to all units and users

The Future

Information technology has not been alone in experiencing change. Over time, the health care delivery system has also changed. In the 1970s, controlling costs was not a prime focus. Today it is, and tools that follow up on costs and quality of care are important. The change from function- to process oriented care means that the patients no longer are treated in only one department or only in hospitals. Today, a patient with diabetes is treated in a unit for diabetic patients where all specialists needed are available and not sent round to dieticians, ophthalmologists, and laboratories. Under what is known as "process oriented health care," the patient should be treated where care can be given at the lowest cost. This policy decision means "outsourcing" patients from the hospitals to primary care and from there to home care and to "self care." In turn, this means that the information about the patient must be available at all these units at the same time and be instantly updated. There is also a need to include images, video sequences, and sound recordings in the CPR.

Patients are also changing, mostly importantly in their attitude. No longer passive receivers of care, they are active, knowledgeable, and demanding, aware of the quality of care. They want access to their own patient records at their own disposal and demand a single unified record regardless of unit or provider. Moreover, they want their records to be presented in ways that they can understand as patients. In Sweden, the decision has been made to find out what changes are necessary in the legislation, and work is under way to form a proposal for the necessary changes in the legislation.

The Next Generation

The next generation of the CPR must be independent from all organizational structures changes. Today many organizations produce one patient record for every unit where the patient has been, and every patient has a number of records, located by using a master patient index where all records are stored. Creating one CPR for each patient will also eliminate the need for the patient to repeat his history.

The next generation of the CPR should be able to present only the information needed at one particular time. This can be done by offering "views" structured according to the health care provider's advance instructions as to which infor-

mation is needed. All health care providers can have a number of "views" for different occasions.

In addition, there must be an agreed upon format for long time archiving of the CPR. Today, there are promising tests underway using XML for that purpose.

The success of efforts to develop the next generation CPR that is user friendly and easy to use will depend upon four factors:

- Cooperation
- Clinical guidelines or treatment programs
- Education
- Standards

Today's medical informaticians can learn from the lessons of their predecessors. They can also learn from other members of the networked knowledge society that is made possible by globally interlinked collaborative IT.

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