About the Beginnings of Medical Informatics in Europe

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Review

ABSTRACT

The term "Informatics" was created in 1962 from two words, information and automatic, and covers all techniques, information concepts and applications of computers. Among them, medicine is the field where we will describe some factors of development in Europe since the late sixties. It took some time for obtaining the acceptance of this new terminology worldwide, but today medical informatics is a well defined discipline which had a tremendous development last decades. This paper tries to recall the context and events from the beginning of medical informatics in Europe.

Key words: Medical informatics, History, EFMI.

1. GENERAL CONTEXT

1.1. An American machine, a European terminology

The first computer, Mark I, "Bessie" for intimates, is born in 1944 from a collaboration of the US Navy and Harvard University, under the leadership of Howard Altken. They conceived and realized a machine that could work "automatically" by following programs introduced in advance (1).

The term "Informatics" was created in 1962 (Académie Française) from two words, information and automatic, and covers all techniques, information concepts and applications of computers. Among them, medicine is the field where we will describe some factors of development in Europe since the late sixties.

It took some time for obtaining the acceptance of this new terminology in the USA. When American industrialists or researchers asked in 1970 what I was doing, they almost always wished to know what was "medical informatics", a European new word that did not correspond exactly to computer sciences. Donald Lindberg, as Director of the National Library of Medicine (Bethesda) played a key role for the adoption of the medical informatics label in the USA and elsewhere in the world.

1.2. An American industrial supremacy, with worldwide applications

In the seventies, IBM was called "White Snow" and the other computer manufacturers "the Seven Dwarfs". IBM benefited of an existing multinational network of vendors for typing machines, and had an appropriate development of computers. Their success was also linked to useful accounting and administrative programs. It was the time of the Hollerith card that everyone had to carry to the computer center. There, each work had to be classified and located like books in a Library, before being processed.

The development of computer applications in medicine followed all over the world industrial and financial projects with some delay. The first applications in Europe after 1965 were clinical laboratories and hospital administrative tasks. Most often existing software had to be adapted locally (2). Other fields were often seen with apprehension. Medical informatics creates a mixture of human and mechanical factors, with a danger of commercial exploitation. Some health professionals had a fear to be replaced by machines.

As postgraduate student in the USA (1970-72) at the University of Minnesota (School of Public Health, Division of health computer sciences in Minneapolis and internal medicine at the Mayo Clinic in Rochester) a good exercise was to write a report on differences between Europe and the USA in medical informatics. The main difference was an integration of development projects by the computer industry with research projects in American Universities. Europe did not have a similar environment as, apart from Siemens, there were very few computers factories. Furthermore, the USA had a serious advance due to the NIH (National Institutes for Health, Bethesda) policy of grants for research projects and fellowships in health informatics since 1961, which resulted in a rapid extension to the Federal level already in 1970.

2. EUROPEAN FACTORS OF DEVELOPMENT

2.1. Individual initiatives and commitments

a) There were so many individual initiatives in the numerous Western European countries that we can describe only a few examples.

At that time, some of the most advanced hospitals in medical informatics were Geneva (Jean-Raoul Scherrer), Paris La Pitié-Salpêtrière (François Grémy), Hannover (Peter Reichertz), but there were already developments

in communities like in Sweden (Hans Peterson), in general practice (for example J. R. Möhr in Germany) as well as signal analysis (O. Wigertz) or hospitals evaluation (Barry Barber, UK) etc.

The first world Congress of Medical informatics organized in Stockholm by IFIP-TC-4, MEDINFO 74, testifies the rapid growth of this new field in Europe (3), as well as MIE European Congresses proceedings, since 1978 (4) up to now. Eastern Europe followed with an important delay.

International medical informatics congresses were organized according to an agreement between European Federation of Medical Informatics, EFMI (5), and International Medical Informatics Association, IMIA (6): a triennial world congress—MEDINFO, and European congresses—MIE's in the years without MEDINFO. I will mention here only the first six MIE's, which started in Cambridge in 1978 (7), Berlin 1979 (8), Toulouse 1981 (9), Dublin 1982 (10), Brussels 1984 (11) and Helsinki 1985 (12).

In order to better understand the large variety of factors that played a role, allow me to take the factors of development to which I was associated in my country, Belgium. Other European countries might have very different experiences and could have reached better results.

The difficulty for a historical overview is the variety of experiences, country by country. Europe is a Union of States, not United States. We might have common projects and even common standards, but we have rarely a central decision point.

In the next section, I will describe my own experience. It has been partly developed in a book that shows the particular development in various European countries in order to obtain DRGs (13).

b) Example of factors for the development of medical informatics, in a European country

In Belgium, the political decision was made in 1968 to separate the University of Louvain created in 1425 in two parts, one , Flemish, remaining in Leuven (Louvain), the other, French speaking having to quit the Flemish territory. This decision obliged the academic authorities to think to long term issues. A new hospital was built (Cliniques Universitaires St-Luc) in the South of Brussels. It was decided to computerize the medical record in complement to many other applications (admissions, billing, laboratories, electrocardiogram, intensive care unit etc)

The medical director, Prof. Paul Lacroix appointed me to found the "Center for Medical Informatics" in 1968, under the authority of Prof. J.J. Haxhe. They accepted my proposal to unify the medical record (create a unique patient number) and to make mandatory in all specialties a "Medical Record Summary" that would list all diagnoses and interventions at discharge. In order to allow international comparisons and linkage with billing data, the ICD9-CM code was chosen, with local extensions, when needed for cases retrieval or for clinical and epidemiological research.

The model developed in St-Luc in a Department of Centralized Medical Archives was visited regularly by

hospital delegations from Belgium and many European countries that adopted a similar system.

2.2.A national scientific policy

There are two models of health care systems in Europe: one inspired by Otto von Bismarck, based on social security", a bottom up approach" taking an amount from workers salary for solidarity after agreement between workers and employers, the other being the national health service, where the State takes an amount of revenues through taxes decided by the government, a "top down" approach, such as William Beveridge plan. Each European country has created a specific Committee that fits in their model of health care delivery system.

In Belgium, where we have a social security system like in Germany and in France, Minister Theo Lefèvre was in charge of Scientific Policy in the early seventies. In 1968, Cardionics, a private company put on the market a program that made protocols for computerized electrocardiograms. The Belgian Society of Cardiology expressed a big concern and discovered the lack of scientific policy in medical informatics. I was associated to their request for educating physicians in this new field by attributing Fellowships and by developing national voluntary projects in medical informatics, among which interhospital comparisons by using the medical record summary such as in St Luc, and by developing applications for the pharmacy and intensive care units. As funds had to be obtained to employ coders and to pay researchers, the Minister (who was also Prime Minister) decided to take unused special funds for major disasters that did not happen. All these activities were placed under the control of the Scientific Policy Committee.

3. EUROPEAN DEVELOPMENT OF COMMON PROJECTS ENLARGING LOCAL OBJECTIVES

3.1. Training program in Toulouse (UNESCO, 1968)

The first international Seminar taken in charge by an international organization in order to offer courses in French on all aspects of medical informatics was held in Toulouse, where several Congresses had been already organized. The UNESCO, located in Paris, financed intensive lessons given by the most up to date University teachers during three weeks. We especially remind the presence of Prof. J. Martin from Nancy, and, as other student, Liliane Dusserre who became teacher in Dijon and played an important role in defining recommendations on security and other ethical questions in the French National Order of Physicians.

3.2. The "Biomedical Working Group" in Luxembourg (European Commission) EEC-BMWG

After my return from the USA where I worked as Research Fellow in the Minnesota Coronary Survey (that was followed by MRFIT, Multiple Risk Factors Intervention Trials) and learned the functioning methods of clinical research and patient management at the Mayo Clinic, I was appointed as member of the "Biomedical Working Group of the EEC" by the Minister of Scientific Policy in Belgium. He nominated me also as a member

of the Belgian group dealing with health informatics projects for the Scientific Policy.

The EMD (Electronic Medical Record) was one of the projects to be defined by the EEC-BMWG, with a plan of development. This justified my presence there.

The President of the EEC-WG was Prof. Peter Reichertz (Hannover University) and the Secretary Mr. Jean Rodesch, a civil servant working for the Commission.

There were two representatives by country, for 15 countries in the EU (European Union) at that time. Three of them became later President of EFMI Peter Reichertz (GE), Rory O'Moore (IRL) and myself (BE).

Allow me to describe the atmosphere when I arrived in this WG. The first evening I was invited by the French members, Prof. Henry Ducrot (Paris) and Mrs. Wolf-Terroine (Strasbourg) in order to better know each other. I had already made the proposal to create a "European MBDS" (Minimum Basic Data Set) for all hospital discharges, that could be linked with billing and costs. They were quite concerned by such project that would allow data transparency. Each hospital would become "une cage de verre" (a cage of glass allowing linkage of medical data to financial data). Who was this young Belgian Fellow, coming back from the US, to make such a dangerous proposal? We ate a delicious lobster. At the end of the meal, they did not seem to be reassured, having learned that I was determined and that my father was a distinguished Economist (University teacher and top civil servant). The next morning, I shared my breakfast with Dr. John Radcliffe, delegate from UK. His first question was: How was the dinner yesterday evening? I answered "excellent". He then said: "don't be impressed by French meals!" I was back in Europe.

3.3. The sinuous road to reach a standard, the European MBDS

It took two years to obtain that the MBDS figures on the list of projects of the EEC-BMWG. As a matter of fact there were multiple activities (supervising funding of cancer research, intensive care, access to literature etc) but the main objective was to create a European network that could serve the pharmaceutical industry.

This ambitious and costly project was initiated and supported by a French-German agreement, with the hope that the pharmaceutical industry could contribute also financially, better than any other medical sector.

One of the major results expected was a more unified terminology or an easy access to an equivalent name for a same product in all European countries.

This required a list of each active principle for each drug. The EEC obtained to have access to some data banks from several Ministries of Health like Italy and Belgium. Such possible access blocked the project. The pharmaceutical industry had accepted that Committees of experts get more details in order to register a product for its reimbursement, country by country. It felt jeopardized if anyone, mainly another industrial group could obtain easily through the EEC network secrets of drugs manufacturing. As this project was stopped there was some money left for other EEC projects.

I was approached in the corner of a corridor by Prof. Wolf-Terroine who announced me that there was a new agreement in the BMWG to put the hospital MBDS as one of the main objectives of the group and that I would be charged to do a "feasibility" study.

My mission was to elaborate a detailed questionnaire on each purpose and each item of a Minimum Basic Data Set to be sent and answered by all member countries. I had then to visit all 15 European countries (several leading hospitals and delegates from Ministries of Health) in order to discuss the answers and to identify ways for agreement on the purposes and content of the MBDS.

This work took four years, from 1976 to 1980, but I learned me a lot on all European member countries. I have been told that a one man study to assemble the opinion of everyone in Europe is probably unthinkable nowadays. This was not the end. Results had to be submitted to an international Conference on Hospital Statistics for population-based health care and epidemiology (9-11 September 1981) in Brussels. An agreement was obtained in the evening of the 10/9/81 in my living room in Uccle, between Directors or Representatives from the EEC (General Directions of Innovation, Industry, Social Affairs) the European Office of WHO (World Health Organization) and IMIA (International Medical Informatics Association). It was approved by fifty experts from 14 countries the next day (14, 15).

3.4. Use of the MBDS in European countries

Thereafter, I was appointed as Advisor to several governments that implemented the MBDS and had to deliver many explanatory speeches.

Among them, let's quote:

- Portugal that made a special agreement with Bob Fetter to use DRGs, with financial support from the US, provided a NATO base could be installed near Lisbon.
- France, where I was associated to the foundation of the PMSI (Projet de Médicalisation des Systèmes d'Information), under the leadership of François Gremy and Mr. Stephan
- Belgium accepted the MBDS in order to change the hospital financing system.
This important reform was initiated by Minister Jean-Luc De Haene
- Italy and Spain expressed the wish to make this information system uniform in the country, but they were regional variations in implementation
- UK, Ireland, Denmark, Sweden and the Netherlands modified their hospital statistics in order to correspond to the European standard and used it for hospital care management.
- Luxemburg and Germany took some delay before adopting the system
- Greece was reluctant to use the MBDS.

4. THE IMPACT OF EFMI (EUROPEAN FEDERATION FOR MEDICAL INFORMATICS)

Besides these official developments through national policies and international projects supported by the Eu-

ropean Commission, scientific societies were created voluntarily in most European countries, most often under the impulsion of IFIP-TC4 (International Federation for Information Processing, Technical Committee 4) that was chaired by Jan Roukens, an EEC civil servant coming from a Dutch Industry. This TC4 was replaced by IMIA, the International Medical Informatics Association.

The European Federation for Medical Informatics (EFMI) was conceived at a meeting, at the Regional Office for Europe of the World Health Organization (WHO), in Copenhagen in September 1976. The representatives of national Health/Medical Informatics societies from ten European countries signed a declaration of intent stating: "The Federation shall be constituted as a nonprofit organization concerned with the theory and practice of Information Science and Technology within Health and Health Science in a European context."

We wish to underline the key role of Albert Weber, from WHO-EUR, to provide advice to the delegates among which Barry Barber was one of the most dynamic.

The objectives of the European Federation for Medical Informatics are:

- To advance international co-operation and dissemination of information in Medical Informatics on a European basis;
- To promote high standards in the application of medical informatics;
- To promote research and development in medical informatics;
- To encourage high standards in education in medical informatics;
- To function as the autonomous European Regional Council

We can consider that the European Federation had three main impacts:

EFMI used the same limits for Europe as WHO. It has to be remembered that in 1976, Western and Eastern Europe were completely separated. This decision allowed to open medical informatics to Eastern countries as well as to assimilated countries like Israël

In order to apply to become a country member, there should be only one scientific society by country. This statement obliged several countries like Italy and Greece to modify their internal structure.

A major role of EFMI has been the diffusion of scientific information through MIE Conference (4) as well as MEDINFO, as during many years the majority of members of IFIP-TC4 followed by IMIA was European.

About international policy, we had a special role after the events of April 1989 on Tian An Mien square in Beijing. MEDINFO 1989 was planned to be held in Beijing and a large number of IMIA and EFMI representatives were asking to dismiss this meeting under the argument that the government did not respect Human Rights.

As former President of EFMI and as Vice-President of IMIA in charge, I defended, on the contrary, that the best way to disseminate Human Rights is to open the

door to scientific communications and exchanges. My argument was accepted by the Americans, among which Morris Collen. MEDINFO 89 was held in two locations: Beijing and Singapore. Shigekoto Kaihara, former IMIA President, told me in Hiroshima in 2009 how happy he was, as well as other Asians that MEDINFO 89 could be held in Beijing because of my strong position.

5. EEC RESEARCH AND DEVELOPMENT PROGRAMS

The European Union (Niels Rossing) initiated research projects in medical informatics called BICEPS-EUROAIM, to which we participated in 1986. However, guidelines had to be provided, taking in account weaknesses as well as strong aspects of medical informatics in Europe.

The AIM Requirements and Strategic Review Board was created by the EEC in 1989.

AIM is an acronym for Advanced Informatics in Medicine. The experts were appointed from the industry and from university research centers. I was chosen as chairman and Gerald Santucci as secretary. We worked during eight months and published the results in a book published by Springer-Verlag (8) entitled Perspectives of Information Processing in Medical Applications in 1991.

We considered challenges and opportunities, dreamed of modernization that could lead to high quality medicine, crossing national frontiers, requiring a collaborative international work and a common infrastructure.

Integration, modularity and security were among the key words used.

These ideas are still applied, nearly 25 years later, first in the numerous AIM projects and now in eHealth.

6. OTHER INITIATIVES

6.1. Education and Training

Apart from the UNESCO one shot session of courses in 1968, the Council of Europe issued recommendations in 1991 for the development of European strategies in health information Systems (16, 17).

6.2. Hospital Management

PCS-E (Patients Classification Systems-Europe) was created in order to diffuse and to adapt DRGs in European countries. A major impact of all these efforts has been the creation of networks of experts that is practically very useful (18).

7. CONCLUSION

There are various ways to describe history. We could have been more systematic, by application or by progress in technology. I was asked to tell more about my story in a large European development process at its beginning. This is why I tried to explain that our actions are influenced not only by our ideal, our views, our ethic and our competences, but also by human interrelations and dialogue in order to make the appropriate choices.

There are fascinating domains that I did not touch,

such as quality of care, patient autonomy by using informatics, equity of care by using telemedicine, medical record structure and terminology to aid diagnosis, training and evaluation of care. This is part of the future of medical informatics.

In a way, I limited my description to areas that were felt realistic enough to be financed through research projects. When a country or an international organization agrees to pay for new developments, this is also a sign of social priority.

CONFLICT OF INTEREST: NONE DECLARED.

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The screenshot shows the EFMI (European Federation for Medical Informatics) website. The header includes the EFMI logo, the website URL (www.efmi.org), and navigation links like 'Add to Favorites' and 'Change Font Size'. The date 'Saturday, 25 January 2014' is displayed in the top right. The main menu on the left lists various site sections. The central content area features a large announcement for the 'STC 2014 - Budapest, 26-29th of April 2014', including the dates '26-29 April 2014' and 'SATURDAY-TUESDAY BUDAPEST HUNGARY'. It describes the conference's focus on big data and lists topics such as data sources, epidemiological studies, vaccine uptake, and data sharing. A sidebar on the left lists 'EFMI COUNTRIES' with flags for Austria, Belgium, Bosnia-Herzegovina, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Iceland, and Ireland. Another section on the right promotes the 'MIE 2014 ISTANBUL' congress, held from August 31 to September 3, 2014, with the theme 'Let's Meet Where the Continents Meet'. The bottom of the page mentions a 'New Issue of Acta Informatica Medica published' on Wednesday, 17 April 2013, and includes a logo for the journal.