Medical Informatics Europe '97
C. Pappas et al. (Eds.)
IOS Press, 1997

From Electronic Medical Record to Personal Health Record

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Abstract. In this paper we attempt to provide a definition and purpose for the electronic patient record, point out the benefits of its use and outline the major challenges in wider implementation that are encountered world-wide. Finally, some trends are highlighted that are believed to play an important role in the future development and use of the electronic patient record.

1. Introduction

Before we attempt to define the electronic patient record we present the setting in which such electronic patient records are functioning and benefiting all the possible users. This scenario may seem an ideal or futuristic situation, but as we will see some parts are relevant to today's situation in many countries world-wide.

First, we assume that the desirable health care system ensures continuity of care. In other words, health care delivery encompassing prevention, diagnoses, treatment and rehabilitation and supporting all the stages with relevant and non-redundant information. This ultimate goal can be achieved by the so-called shared care scenario. The professionals of all the stages support each other and share information for better care delivery and ultimately for the benefit of the patient. This patient-centred shared care builds on health telematics networks and services, linking hospitals, laboratories, pharmacies, primary care and social centres offering to individuals a "virtual healthcare centre" with a single point of entry. The information shared by all care providers is patient health-related information which is comprehensive, reliable and confidential. A particular example of such a scenario are the managed care organisations which are growing mostly in US and which focus on maximising the outcomes with lowest possible cost.

Second, let us briefly see the different stages of usage of informatics in the field of health. The first stage is the one where the informatics applications and services are used to make the existing work-processes of all the health professionals more effective. For example, the scanned paper forms that are used in the hospital are kept for easier storing, retrieval and communication within the hospital, the laboratory systems that give immediate access to the lab results, and direct links to medical libraries (e.g. medline) or databases instead of faxing or time consuming orders by post. And of course, the most common example are the administrative systems in the hospitals for management purposes. The second stage refers to usage of tools that lead to or support the re-engineering of health system and processes and that way contribute to the improvement of quality, access and efficiency of care, or in other words, support the continuity of care. One example is telemedicine services such as teleconsultation and telediagnosis that bring the medical expertise to the point of need. Another example is the emerging health networks on regional or national basis that allow

communication of relevant and confidential data between the primary and secondary care, public health authorities, and other relevant parties providing seamless care. In the future such networks will also reach private homes supporting health status of people and provide, hopefully certified, health related information. There is a third stage of use of intelligent informatics tools that drastically re-engineers the way healthcare professionals store and apply knowledge. We will not expose this stage here but only point to one example of knowledge coupling and problem oriented medical record [LW].

The Electronic Patient Record (EPR) is defined as digitally stored health care information throughout individual's lifetime with the purpose of supporting continuity of care, education and research, and ensuring confidentiality at all times. The EPR is not a goal in itself, but a tool for supporting the continuity of care and consequently the quality, access and efficiency of health care delivery. In other words, the enabling factor of the patient-centred shared care is the availability of both clinical and administrative patient data through electronic patient records that are accessible, secure and highly usable in the European multilingual environment.

From this definition we can immediately differentiate from the medical record systems (distinction is made between the EPR and EPR system) that belong to the first stage of use of informatics tools in health care. The administrative systems or departmental clinical systems, or even stand alone general practitioner's systems are not examples of EPR system, but rather limited scope electronic medical systems or computerised medical systems. Thus EPR supports the decentralised network of health care delivery centres that slowly replaces the hospitals which often are the only centres of care delivery and care related information.

The experts in the field of medical informatics and telematics have been trying for many years to describe the ideal EPR on both sides of the Atlantic. In 1991, the Institute of Medicine in USA published a report called "The Computer-Based Patient Record: An Essential Technology for Health Care" [IOM], describing the requirements of EPR, and making recommendations for the future. In the same year in Europe, the requirements of an EPR were formulated in the work-programme of European Union R&D Programme called AIM-Advanced Informatics in Medicine, now called Telematics Applications for Health [AIM]. Further recommendations were agreed in the AIM/CEN Workshop on Medical Record in 1993 [MRW] and its follow up the EU/CEN Workshop in 1997 that was a part of MIE '97.

2. The attributes and benefits

The benefits of using an EPR system are not easy to measure quantitatively and of course depend on the attributes of such system. The above definition leads us to some functional requirements or attributes which in their turn point out to the benefits. Here we mention briefly the following attributes, accessibility and availability-continuous access to patient data or timely access to other information resources, reliability-ensures data integrity and permanence of original information in agreed format and for given time, usability and flexibility-support multiple user views and user-friendly interactions such as input and output of data, integration-enables integration of different administrative and clinical systems, performance-provides information normally within few seconds, confidentiality and auditability- provides an audit trail that documents the interactions, and authentication of information using user identification, e.g. digital signatures. There are many other attributes that one could list of different levels such as facilitation of clinical reasoning,

support in measuring and managing costs, link to knowledge bases and support monitoring and outcomes etc. A discussion on these can be found in Healthcare Informatics, May '96 issue. The requirements and the "nice" features list will be growing in the future as the physicians and the patients realise the potential of such EPR and other informatics tools.

It is not difficult for any health professional to see the direct benefits of using EPR and having both administrative and clinical data that are accessible, comparable, communicable, and confidential. Here we will just point out few. In the area of preventive care we have for example the provision of information to the health professionals through automated reminders and alerts that could reduce the medication errors and adverse drug reactions. Also it is a source of data for population's health status allowing for monitoring and decision making e.g. immunisation strategy. In the area of diagnosis, previous patient encounters and summary information such as diagnoses, lab tests or images are quickly available. This information together with links to knowledge in the form of research papers or clinical databases support the decision making. In the area of treatment, the EPR's links to knowledge can provide internationally agreed guidelines, outcome can be better monitored and assessed, and a multi-disciplinary environment for treatment and rehabilitation can be supported. The benefits are also obvious for the managers and healthcare authorities. Better data for resource management, for automation in the referral process and better use of specialists, for quality assurance and financial forecasting, and for support to regional or national decision making such as decisions on reimbursement of medical procedures. There are several studies that indicate direct financial benefits [KR] of using medical records in outpatient setting, such as reduction of labour costs for coding and billing and reduction in cost for repetitive tests. For general practitioners savings come from better management of their practice, and simply, less time searching for information which translates into more time with patients. Of course one should not forget the initial costs, the extra expenses for the support personnel and operation of such systems. There are too few EPR systems with the above mentioned requirements implemented to have concrete data on improvement of quality of practice or return-on-investment analysis.

3. Present situation and implementation challenges

How many EPR are installed and functioning around the world? Very few, if any, as we have defined them with all the nice attributes. Many if we relax all the nice attributes described above and see the situation of the electronic medical records that are used in the medical practices such as general practice offices or in different hospital departments. The electronic medical record systems or practice management systems for general practitioner have so far the highest penetration. They are very popular in countries that have strong tradition in the primary care such as United Kingdom, Ireland, Netherlands, Denmark and others. For example, in United Kingdom 90% of GPs have computers and 70-80% of them use them to keep patient data and 15% have "paperless" offices. In Netherlands, 80% of GPs have computers but only 40% use them for electronic medical record [JDM]. In other countries the GP systems are not commonly used. For example in some regions of Spain the use reaches 20% in other regions is below 1% and the overall figure is around 4%. In the hospitals the most common information systems in use are the administrative and management hospital information systems (HIS). Not many hospitals in the world have information systems that integrate both clinical and administrative patient information and that are sharable by different specialists and other health professionals. Most of the examples are pilots that are supported by Research and Development funds such as the

European Union Telematics Applications Programme for Health [IIA1] which is presently sponsoring over 100 projects in the area of Health Telematics and many of them in the area of EPR (see www.ehto.be). The EPR systems are being developed and validated in isolated or regional network settings. Many EU countries such as Denmark, Finland and Sweden support national projects and strategies on EPR and regional health telematics networks.

Why are there so few systems available and even fewer implemented? The market seems to be booming, the publications on the subject are rising, conferences on EPR are attracting users and providers in hundreds (in US in thousands). It is enough to search the Internet with the keywords electronic patient or medical record to see the hundreds of references. So why don't we have them after 30 years of research and development? We attempt to give an answer in presenting the problems and challenges in the following six categories.

• First, the organisational and cultural matters relating to health care delivery. This applies to countries or regions where the organisation of the care delivery cannot ensure continuity of care with or without information systems. For example in Greece the are no general practitioners and the level of primary care is minimal. People can choose from an abundance of specialists or go directly to any hospitals for minimal health problem or serious emergency situation. The information about each patient is registered for each episode of care and rarely used in the next episode even within the same institution. Many cultures do not support the idea of sharing the patient information. Each professional is trained to trust nobody and is even penalised for relying on information of other colleagues. Most of the countries in this category are currently considering some form of health reform primarily in order to control the rising cost of health care.

• Second, is the acceptability of EPR pertaining to technology and human related factors. The main challenges from the technological point of view refer to the storage, maintenance, communication and retrieval of multimedia information in different technological platforms and heterogeneous database systems, that may be geographically distributed. Integration and interface of multivendor platforms and the development of health sector specific middleware and applications has recently received lot of effort by research and development projects such as Synapses and Hansa (see www.ehto.be). Also some large companies that need to keep the initial "legacy" systems running in the hospitals by interfacing them with new departmental systems and updating to new technologies. This integration effort is critical since the number of different purpose systems (administrative, insurance, clinical, nursing etc) is rising and it is not uncommon to see within one hospital department three screens or three computers each for one specific part of patient care and management. In this area the new intranet networks prove to be the answers to many of the integration and communication problems. Also, the functionality that should be supported raises further research challenges, such as real-time content-based indexing and retrieval of multimedia information, development and maintenance of large active heterogeneous databases, development of high-speed telecommunications networks, etc. The above give rise to series of challenges from the Human-Computer Interaction (HCI) perspective, related to capturing and input of data in EHR, as well as the presentation of the recorded data in a variety of forms, media and output systems, etc. In particular, specific technological areas that need to be addressed concern input and output devices (e.g. pen-based input, speech input), 2D and 3D interaction techniques, intuitive interface metaphors, mobile systems, multimodal interfaces, tailorable and adaptable interfaces, more natural access procedures (e.g. speech interfaces), computer-supported cooperative work intelligent interfaces, user identification procedures, and user interfaces for mobile services [IIA2].

Finally, we would like to emphasise that the 3 priorities of healthcare professionals are speed, speed, and speed. In other words, the only chance for the informatics system to be successful is to eventually make the work more efficient without lengthy adopting period.

• Third is standardisation of EPR parameters which has a large impact on the development of EPR systems and the market in general as we will see in what follows. The standardisation issues can be grouped into the following categories:

- record architecture standard, that is the agreed structure that can accommodate all types of data and support different views and at the same time preserve the meaning and the context. This standardised architecture should be general model of the record so it can enable the developments of many different systems with a particular instance of this architecture.
- standardised terminology that is necessary in order to preserve the meaning, for proper coding of diseases and classification of medical procedures, for any possibility of multilinguality and possibilities to link and updating other knowledge sources. The work on terminology is long lasting and difficult and requires concerted effort of many disciplines and countries. Recently an European Federation of Classification centres has been established within the project GALEN (www.ehto.be).
- standards for communication of the record among the different users which is the fundamental feature of the EPR. The standardisation of the exchange format of course depends very much on the previous two categories since access to EPR and the "virtual" displaying of requested information one needs an object dictionary of terms and objects related to the structure and the terms in the record. There is a lot of progress expected using the intranet approach for institutions and internet based communications for the regions. There is also in parallel large effort by the projects and standardisation bodies in the area of Electronic Data Interchange (EDI) to standardise some particular messages, for example laboratory input output, discharge letter communication between hospitals and GP.
- standards for the security features such as digital signature, digital keys and other authentication systems. Most of the security applications and technologies are not health sector specific and the development is mainly pushed by the large financial or military institutions. The issues of security are closely related to the requirements of the confidentiality that is inherently in the definition of the EPR and will be also be legally required by the national legislation.

In Europe the standardisation organisation is CEN (Committee Europeen de Normalisation) which has technical committee TC 251 responsible for medical informatics (www.ehto.be) The TC 251 gathers experts from all over Europe to propose standards. The first working group is responsible for the standardisation of some of the above issues for the last few years and resulted in some pre-standards. The slow procedures and lack of funding are the major obstacles to fast adoption of these standards. In US the approach to standardisation is quite different, it is more industry push, and the responsibilities for the medical informatics is spread out over many subcommittees (www.medrecinst.com).

• Fourth, are the legal requirements on the confidentiality of personal data and requirements on storage and authentication of patient related data. It is clear that unless a law provides

the possibility for patient records to be kept only in digital form there will be no wide implementation and EPR systems will be used only in small pilots "digital islands" or specialised departmental and messaging systems. Thus the medico-legal framework has to address the issues of confidentiality and privacy, permanence of data, and allow for digital signatures and authentication of systems. The European Council and Parliament have adopted on 24/10/95 directive on the processing of personal data and free movement of such data (95/46/EC) which needs to be implemented by 24/10/98. At this moment this directive is of course applicable only to the EU Member States, but in the future other countries such as the countries of central and eastern Europe that will enter the EU will have to harmonise the legislation accordingly. Briefly the directive calls for principles relating to data collection, gives criteria for making the data processing legitimate and focuses on some special categories of processing. The issue of patient identifier (the necessary link between all the distributed patient data) is explicitly left to be dealt by the Member States. From the principles relating to data collection it is important to note that "Notification authorities" will be established in each Member State that will authorise any collection and further processing of personal data. So if the health sector does not get some gross deal with these authorities the laws pertaining to collection and communication of patient data will remain ambiguous and will slowly be shaped by the law suits that will arise in the future. Consequently the wide implementation of EPR systems will go through some turbulent time in the near future. It is suggested that "opposition" laws are promoted that are concerning the responsibilities for lack of collecting or transmitting patient data that could have significant output in the care process.

• Fifth, are the industrial and market issues that are determined by the demand for EPR systems and the willingness of the industry to invest in good quality records. In general the health care market is seen by the industry as large in size but not highly profitable mainly due to lack of standards (mentioned above) for the EPR systems and related applications. The different legal requirements, different language and specificity of work processes of each country or region lead to high cost of development and customisation. It is often a case that the systems are custom build for each hospital since each hospital believes that it operates differently from the others. As a result the export across country or language borders of EPR is marginal. The situation is very fragmented in Europe. Most of the countries have a few dozens providers of mostly electronic medical records which have very few installations which are not interoperable or which cannot communicate. Exceptions are countries like Norway, Iceland, and Netherlands where the market has consolidated or countries like Greece where it has not picked up yet at all. The companies are not willing to cooperate so that each company has to reinvent the wheel which is very costly [SD]. In Europe one can observe the lack of larger companies that are willing to provide the platform on which the smaller and medium size companies could build their plug-and-play solutions. Finally it is sufficient to point out that the laws governing the health care market are not the competitive for-profit laws but slow public decision/procurement laws that result in low overall investments for information technology (1-2% of the overall budget) compared to other areas and industries that invest 5-10% of the budget. This leads us to the last point which is probably the most important.

• Sixth, are the lack of vision and leadership of the health care managers and health authorities and the lack of willingness to re-engineer the health care processes for the benefits of the quality and efficiency of care delivery. Some European countries such as Denmark and Sweden have in the last couple of years initiated strategies for the EPR

implementation but it is still early to see the results. It is also understood from the exposition above that the successful implementation EPR goes hand in hand with re-engineering of the health care processes which is time and effort consuming process. Other countries still lack the vision and initiative in this direction. The managers are usually squeezed one between the demands of the health care sector related to direct care and cost-containment pressure from the authorities. As result the decision on the information systems or EPR systems are mostly short term needs and cost or "wait and see" policy for the final solution. One good example of national strategy to boost the computerisation of medical practice is in France where by law by the end of '98 the physicians have to submit claims for reimbursement to the insurance companies electronically. It is expected that the percentage of computers in the physicians office will rise from 20% to 90% in '98 and together with that the use of electronic medical record that will provide the basis for wider implementation of EPR.

As a conclusion to this chapter one can see the complexity of the challenges and the necessary role of all the players. The healthcare professionals that will certify and accept to work with new tools for their benefit and the benefit of the patients, the authorities to understand the vision and take decisions for re-engineering and legal framework, the researchers to provide new solutions to problems mentioned above and industry that adopts standards and provide inexpensive and interoperable solutions. No isolated initiative by any of the relevant groups, healthcare professionals, managers, authorities, researchers, industry, and eventually the people, will lead to successful EPR and widely accepted EPR systems. Only a concerted effort of all the players and groups can succeed. The immediate question that can be raised is: Who cares for the big picture? The healthcare professionals care for the part that improves their work, managers care only for the data that they need, and the industry to maximise the profit etc. Thus the challenge is posed to national, regional or non-profit organisations to bring all parties to work towards EPR that supports the continuity of care and benefits all. Along this line project PROREC (www.ehto.be) has been launched by the European Commission that creates the environment in some EU countries for all the players to collaborate and to promote the use of good quality EPRs. Also other countries such as USA (www.cpri.org) and Canada (www.cihi.ca) established and promote organisations which could provide such environment. There is lot to be learnt from the past experiences. All those that are in some way concerned with development or decisions on implementation are therefore strongly encourage to take the time to review the international developments and carefully examine as many pilot sites as possible.

4. Future trends

So far we have not mentioned one particular and very relevant group, namely the people. Here we mention people and not patients since we would like to stress the focus of the future health care on the non-care sector, namely the health promotion and prevention.

On one hand people are "thirsty" for health related information. As the HP/HIMSS study '96 indicates, it can be found in the May '96 issue of the Healthcare Informatics journal (A. Wiesner publisher), the most significant healthcare-related computer development affecting the average consumer was access to on-line health information and services from home. Other studies indicate that 25% of the internet queries are health related. It is a trend, especially in US, that the people start creating personal health records where they register health related data such as self-monitoring of chronic illness, make dietary notes, sport and exercise performance, behavioural activities and moods etc.

On the other hand, "consumer satisfaction" is of growing importance not only in the privately managed care delivery systems, but also in the public systems. In the EU Directive mentioned above patients are given the right to be informed about the use of health data, the right of access to his/her records, and the right to object to some data. Both the tendency of people to know more and to actively participate in the health promotion, prevention and care together with the rights that will become a standard legislature orient the development of informatics systems that support these tendencies. In particular the EPR will not only be accessible to the patients but also incorporate their views and notes. Thus we could see in the near future the developments of personal health status monitoring and support systems at homes that interact with personal health records and complete the picture in the continuity of care scenario.

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