Electronic Health Records in Sweden: From Administrative Management to Clinical Decision Support

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Abstract. Computer support for health care started in Sweden in the mid-1960s, with a series of pilot tests using clinical records at the Karolinska Hospital. This had very little impact in health care due to its limited volume and scope. In addition, the first automation of chemistry laboratories that created many benefits in the form of increased efficiency from the early 1970s, rapid results delivery and the possibilities of quality control also occurred in the mid-1960s. The 1970s and first part of the 1980s saw the independent development of several patient administration systems, based on central mainframes in the counties, as well as a large number of dumb terminals in the hospitals and later also in the outpatient clinics. From the early 1990s, we saw an explosion of primary care electronic health records with twenty-seven different products in 1995.

Keywords: Electronic health records, Melior, patient administrative system, PAX, Swedestar

1 Introduction

Health care is a large part of modern societies, accounting for nearly 9 percent of the GDP and a similar proportion of the labor. Although it is also a person-centric manual service, it is a business that is very information rich and in which knowledge is rapidly developing. It has been stated that owing to the large and growing amount of information that needs to be managed, a situation where the capacity of the unaided human brain no longer meets the requirements is approaching. There have also been many interesting attempts, using computers for a very long time, to provide decision support for medicine, but few of the advanced AI techniques often first developed for medical problems have actually had a broad impact.

The very first account of automatic decision support for medicine dates back to the thirteenth century with Ramon Llul, who was a scholar in Mallorca. Llul was

knowledgeable in the mathematics of Arabia, as well as in European Medicine, and a practicing physician that influenced Leibniz in the early theory of computation. Llul invented a machine, now called the Lullian Circle, which consisted of three paper discs inscribed with alphabetical letters or symbols that referred to lists of attributes. The discs rotated individually to generate a large number of combinations of ideas. For medical decision support, one of the circles described possible symptoms, the next indicated possible causes/diagnoses, and the third included a set of remedies or treatments indicated by turning the circles.

Computers in health care, as studied in the scientific field of medical informatics, were used in a large number of areas and are today essential in many fields such as digital imaging and bioinformatics analysis of DNA and proteins.

However, we dedicate this paper to the history of computer support for routine tasks in health care where information, often in the form of a simple line of text or a single numeric value, manages both the medical understanding of a patient as well as to improve the management of the processes of investigation and treatment. Estimates show that nurses and physicians spend about 40 to 50 percent of their working time on information management in a broad sense.

Despite many internationally advanced and pioneering projects, it has taken quite a long time for the health sector to use the advantages of computer technology. This paper describes the early developments in Sweden, until 1995, and discusses some of the reasons for the somewhat slow, large-scale introduction.

2 Materials and Methods

This paper is based on a literature study and on interviews with Gert Ljungkvist, project manager at SPRI, the Swedish National Institute for Health Services Development owned by the Department of Health and Welfare (Socialdepartmentet) and the Federation of County Councils (Landstingsförbundet). In Sweden, this institute played a very important role in the development of good practices for documentation, first in the paper world, and computerized records from the early 1980s. We have also used the documented personal accounts of early Swedish IT history, particularly those of Hans Peterson, Paul Hall, and Torsten Seeman [1–3].

3 Results

Computer support for health care started in Sweden in the mid-1960s, which at an international level was very early. This was a series of pilot tests with clinical records at the Karolinska Hospital in the Stockholm region, which was using batch processing. Although these tests achieved some international fame, they had very little impact in health care due to their limited volume and scope.

The automation of chemistry laboratories and various administrative systems soon followed. It was not until the mid-1980s that computer support for medical records really started to emerge with an explosive development in primary *care* and with hospitals generally following fifteen years later.

3.1 Laboratory Systems

From the early 1970s onwards, the next step of automating the chemistry laboratories created many benefits in the form of increased efficiency, rapid delivery of results and possibilities of quality control.

At that time, all laboratory instruments delivered readings in analogue form, which was unsuitable for data processing and therefore required digitization. The first computerization step was therefore to develop or introduce commercial analogue for digital converters and equipment, which triggered a precise reading rate. Thereafter, automated data processing grew rapidly within the laboratories and with automated analysis instruments; the Swedish AutoChemist, the English Vickers, and the Swiss Greiner analyzers all had interfaces that made them compatible with most computers. The automated processing of the laboratory data increased productivity and made it possible to achieve a much higher level of quality. This also meant that one could send laboratory results to the wards and primary care units electronically, where they arrived at the same moment, as the results were ready at the laboratory.

The laboratory data was also stored in databases at the laboratory, which made it possible to obtain a cumulative laboratory test report per patient, even before they installed computer systems in the clinics. As hospitals had installed PAS and electronic health record (EHR) systems, they interfaced with the laboratory systems and both requests and transmitted the results automatically.

3.2 Patient Administrative System – PAS

The 1970s and first part of the 1980s also saw the independent development of several patient administration systems, based on central mainframes in the counties, as well as a large number of dumb terminals in the hospitals and later also in the outpatient clinics. These managed invoicing as well as the allocation of hospital beds and certain related tasks.

One of the systems developed was PAX, in Gothenburg. This was created in-house, after a number of other incompatible systems had been installed, tested and disqualified. There were many discussions and arguments about which system was the best and should be used, before it was decided to develop a totally new system based on the experiences from the others and peace was established, thereof the name PAX.

They developed the basic version of this new system in two years and installations started in 1988. It took several years to install the system due to financial problems with supplying all the wards with the necessary equipment and the training of the staff. They continuously improved the system during the years and it is still in use in the region of Västra Götaland and the county of Dalarna. Another system was called PAS in SLL, the county of Stockholm; the third largest region around Malmö in Skåne developed yet another system that included diagnosis codes, codes for admission, and referrals among others.

3.3 Primary Care Record Systems

Due to the difficulties of creating computer support for the clinical staff, physicians, and nurses, it took almost twenty years after the first trials before electronic health records made their successful entry into primary care rather than in the more demanding general hospital sector.

One of the most interesting systems in Swedish primary care was called Swedestar, introduced in Lerum [4] and Sundbyberg in 1984, which is still, with minor modifications, in use in several places. Swedestar was a modification of Costar, developed in Boston, closely associated with the MUMPS operating system that included an integrated database function. A similar development in Finland was the Finnstar system. An important and novel idea at the time was to record all clinical information according to certain keywords from a defined local terminology. This allowed both a fast selection of the relevant parts of individual case histories for presentation and, perhaps more importantly, the easy and efficient compiling of data from groups of patients. The latter can be used both for scientific studies on various clinical issues and for quality management of the core clinical work. The system was based on a local minicomputer server for a primary care centre with asynchronous terminals, later PC workstations. This relatively innovative system came from the high-tech advanced, academic environment of Harvard.

The next step was the proliferation of a large number of small PC-based systems that in many cases were more like word processing systems rather than for the advanced management of structured data. They were often developed by a physician in co-operation with one or several, more or less, self-made software engineers. Data from a SPRI report [4] illustrated in Fig. 1 shows the rapid deployment of record systems.

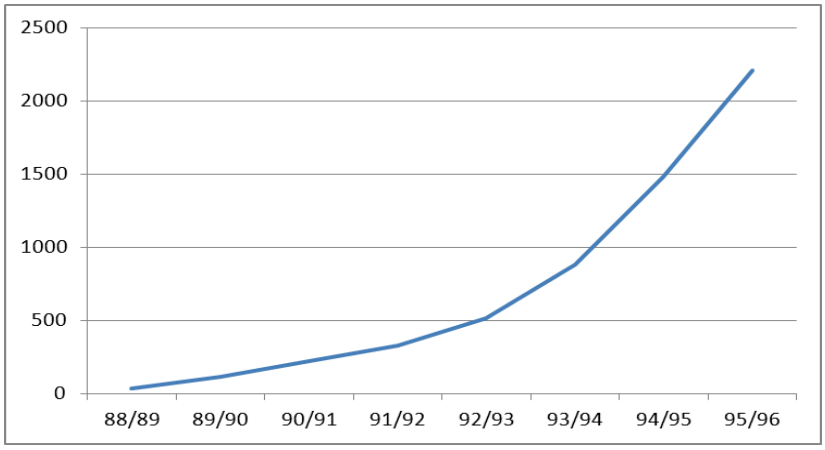

Fig. 1. Number of installed EHR systems in Sweden 1988–96.

In 1994, EHR systems operated in 85 percent of the primary care centers. As shown in Table 1, there were twenty-seven different products available on the

Swedish market [5]. Note that the Melior and Bedside systems were intended only for hospital care.

Table 1. Systems for electronic health records in Sweden 1994.

System name	Supplier
AMA	Mediflex Data AB
APEX	DDE Sverige AB
Axept (formerly called Aesculap)	INEQ AB
Bedside	Celsius Information System
BIOSIS	Health Allocation System AB
BMS journal	Bonjour Medical System AB
Dialog Journal	Celsius Information System
Dr Grans Datorsystem	Gran Data AB
Infodoc	Sysdeco Profdoc AB
Journal II and Journal III	Sysdeco Profdoc AB
Journalia	Journalia AB
Mac Adapt	Frontec Care System AB
MacDoc II	Esmeralda AB
Medex	Medex Sverige AB
Medicus	Data 16 AB
Medidoc	Medidoc AB
Medilite	PCD Applitron AB
Melior	Siemens AB
Mia vård	Infoservice Sweden AB
Patientjournalen	Patientjournalen AB
PC-Praxis	Lap Power
PMS	Bergsjö Data- och Systemutveckling AB
Promed	PRO International AB
Swede Star 2.0	Celsius Information System
VANIA	CAP Programator
VAS	CAP Programator Stockholm AB
WordPics	DAFA Syd AB

We believe that an important reason for the popularity of these small-scale developments was the sense of participation that the clinical staff felt in being able to influence many details of the systems. This was in contrast to the later production of in some ways more advanced systems introduced through the central IT management of the various counties and often developed by large, or at least somewhat larger, software companies. Only a few clinicians were able to influence the design and many felt alienated from these systems.

Also contributing to the popularity of the small-scale systems were the improved user interfaces, employing windows techniques especially designed for the record systems and later based on Microsoft Windows with a mouse and with color.

Unfortunately, they had already forgotten some of the important design principles of earlier systems from the 1960s such as using defined terminologies and structuring data based on headings and subheadings useful for keyword-based searches and for the compilation of statistics.

The developments of electronic health record systems during the 1990s and into the new millennium included a large number of integration projects that had aspects such as laboratory referrals and results, electronic prescriptions and, with the patient administration systems, national and regional population registers and reporting for invoicing.

There has also been a successive return to the goals of recording clinical data in structures based on both process analysis and medical ontologies as well as using more internationally based health terminologies that are very large compared to those used in other sectors. The current and very promising clinical terminology SNOMED CT, translated into Danish and Swedish, contains some 308,000 concepts with 900,000 terms and 1.5 million relations.

3.4 Hospital Record Systems

The large-scale use of electronic health records in hospitals came considerably later than in primary care. However, already by the 1980s, a number of specialized record systems were developed particularly for various university hospital departments. Nevertheless, these mainly complemented the paper-based record systems rather than replaced them. However, we will describe two early hospital implementations. One is the adoption of what was really a primary care system in Ystad; the other is the comprehensive development in Gothenburg, first installed in 1994.

The Ystad Case

The first Swedish hospital to use comprehensively an electronic health record system was Ystad, a small hospital in the southern Swedish region of Skåne. This 190-bed hospital also had 74,000 outpatient visits a year, including 21,000 for acute illness, which installed the Swedestar system.

In 1989, HC Lennér, chief physician at the department of internal medicine, initiated the project [6]. The hospital management was enthusiastic, and although they received some external grants, the hospital financed some 80 to 90 percent of the investment costs from their normal budget, believing it would pay off. They divided the goals into two sets – short- and long-term goals.

The short-term goals include:

- Less manual work for notes, referrals, and lab results,
- More efficient care through better access to information,
- Support for nurses and the evaluation of the nursing care,
- Possibilities for change and trials of new processes in outpatient clinics and clinical wards,
- Improved privacy protection,
- Improved work situation for the assistant nurses by providing more direct patient care and reducing the time spent on paper work.

The long-term goals include:

- Improved assessment of the production and costs,
- Improved quality management,
- Improved competence of staff.

They first used the system in 1991 in the clinical wards for internal medicine and certain outpatient clinics. There were many initial difficulties with frequent stops of the system and much integration was required for referrals and lab-test results that were not ready. Interestingly, the ways of working with records and rounds changed. Doctors and nurses now first sat down in front of a computer and discussed all the patients and then the doctors made their rounds alone, with very little documentation and no computer support. Not everyone applauded this approach. In 1994, they computerized almost the entire set of hospital's records. In the overall assessment, they at least partially met the goals in all aspects, but 25 percent of the staff felt that the computer records functioned worse or much worse than anticipated.

Melior – The Sahlgrenska Development

Sahlgrenska University Hospital is a large teaching facility in Gothenburg. They started to develop their own EHR system in 1988, using a then rather modern Microsoft technology and allowing different departments to choose their own key words and specific graphical user interfaces to create an efficient and user-friendly display for the presentation and collection of data. Although this was very popular, it caused problems for the doctors and nurses when they moved between the wards, because they did not recognize the screen-layouts. Therefore, they decided to develop one common user interface, which was very similar in appearance to an ordinary paper-based health record. This version was ready in 1993 and the installation began the following year. Unfortunately, it had taken a long time to install the system in the whole hospital for the same reasons as with the PAX system.

3.5 Attempts to Standardize Systems for Interoperability

From the early 1990s, there have also been several attempts to develop standards for record structures. In Sweden, the government organization, Swedish Institute for Health Services Development, SPRI [7], had an important influence in setting standards for certain elements of records, actually starting with the paper-based ones of the 1980s, but also used many in the 1990s EHRs. European standardization started in CEN/TC 251 from 1992 onwards and the first elements of the Electronic Health Record Architecture appeared in 1995 under the leadership of doctor Petter Hurlen from Norway. An object-oriented information model followed these design principles in the pre-standard 13606 in 1999. This in turn was further developed into what is now state of the art in electronic health record architecture. Based on the two-level modeling, it uses so-called archetypes for specific clinical purposes that represent constraint models of the relatively small reference model. Since 2008–09 this has been both a European CEN and an ISO standard and thus a national standard in all the Nordic countries.

4 Discussion

The paper presents how computer support in primary care was rapidly developed and implemented on a large scale in Sweden during the early 1990s. At an international level, this is quite early, although our neighboring countries had similar developments but somewhat later. One reason has been the public financing of health care in Sweden through the now twenty independent county councils. These had enough financial strength to support the introduction of record systems in all the primary care centers of their respective areas. The general size of a rather large group practice of four-to-ten doctors and perhaps ten-to-thirty other staff members also meant that there was a power of scale that facilitated the investment, installation, and management of the small server-based systems on a local area network with relatively advanced software. In many countries, even in European ones such as France, a single doctor's office largely manages primary care and there is little capacity to manage a computer system let alone its development.

It is interesting to note that during the rather few years of the early 1990s, when this market took off, there was a huge proliferation of at least twenty-seven different products, developed with a quite similar range, although some of them were imports from Norway, Denmark, or Iceland. This was clearly too many and ten years later only four remained as commercial products, although in some locations many of the early systems are still running. Three of the systems used in 1994 are now among the leaders in terms of number of users, Journal III, Melior, and VAS. Relatively little has happened to them in fifteen years, even if no new installations occur.

It is noteworthy that Electronic Health Record systems rarely succeed in other countries than in their country of development; many also have problems reaching beyond the region in which the company is located. In some respects, a hospital EHR system is much more demanding. Use was still very low in 1995 and it was not until 2009 that as many as 85 percent of hospital wards were using computerized records.

The goals of the early pioneers not only targeted improving the efficiency of routine activities in health care, but also the prospects of easy and comprehensive follow ups of medical results, as quality management and research into the future were often mentioned. Unfortunately, the systems of the 1990s that still dominate the scene do not provide such features, partly because medical facilities did not fully appreciate the difficulties of standardizing EHR structures and their associated medical terminologies.

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