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The Journey towards a National Healthcare Data Network in Denmark

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Abstract. For a start this paper contains a short historical overview showing important steps in the ICT development in Danish healthcare with emphasis on the data network and communications. In 1988 the development of a national healthcare data network began. It was initiated with experiments with an EDI message for prescriptions, exchanged between GPs and pharmacies. Later more parties, i.e. hospitals, laboratories, municipalities etc. were connected to the network. In the year of 2000 a great part of the paper based messages exchanged between the parties were developed as EDI messages, standardized and in daily use by all parties. The paper ends by describing the development since year 2000, when the strategy was supplemented with new methods, where the exchange mechanism was changed from sending data between parties to sharing data through central national repositories. The role of legislation in the field is discussed.

1 Introduction

As a patient being treated by a healthcare system you meet a number of parties (such as your own general practitioner (GP), hospital departments, specialists, laboratories, municipal social services, etc.) who need to cooperate in order to offer you a proper treatment. In this paper the various parties are named *actors*.

This cooperation calls for effective and secure ways of exchanging patient data, such as illustrated in fig. 1. The interaction between the actors, and the use of ICT to facilitate and improve the exchange of information is the main topic addressed in this paper.

2 Historical Overview

The ICT-development in the healthcare sector has been long and troublesome. Changing of legislative regulations, work-flows, role and responsibilities and missing or shifting political support have been some of the influencing factors in the development. Some important trends are shown in fig. 2.

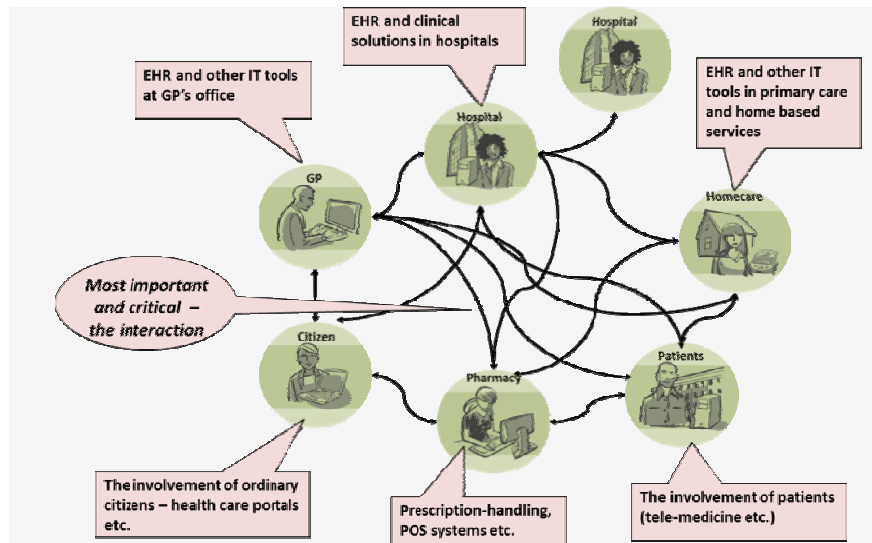


Fig. 1. The ICT enabled exchange of information in the healthcare sector and involved actors

In the 1970s the most widespread applications were laboratory systems and patient administration systems in hospitals. The patient administrative systems were required, because the Danish Medical Association demanded statistical data on patient treatments from all hospitals in the early 1970s.

In the 1980s hospitals introduced ordering systems, booking systems and electronic healthcare records (HER), GPs took electronic healthcare records on PCs (developed by small it-companies in collaboration with it-interested doctors) in operations, and billing and stock control systems in pharmacies were implemented.

The systems, however, were not communicating with other actors' systems. We were talking of local initiatives and local systems.

In 1990 the so-called *Amager Experiment* took place. The aim of this project was the electronic interchange of prescriptions between GPs and pharmacies, information which was previously handed over via telephone. This could be considered as the start of building an infrastructure and a national healthcare data network aimed at supporting EDIFACT based information exchange (asynchronous exchange of messages of the type "one named actor orders a service from, or issues a request to another named actor"). This experiment and the development of the data network will be described in this paper¹.

The above information exchange pattern, where independent ICT systems on request or at certain events exchange data with designated partners, is well suited in

¹ Another paper presented on this conference shows an alternative view on the development. The paper, *The Electronic Healthcare Record: The first national strategy . . .*, deals with one of the most important applications, the support for hospital personnel – in form of the electronic healthcare record.

cases, where few actors are involved and when they all are known beforehand. But if actors get involved in the patient care without prior notification and instruction from another actor, or if an actor needs actual and up-to-date patient record information, this exchange pattern proves insufficient. Here you need a central coordinating ICT system, which enables immediate on-line access to updated information.

However, the first step towards a national coordinated system with a centralized on-line database came as an effect of national legislation in 1999. All medicine on prescription receives public subsidy, i.e. the patient only pays part of the price of the medicine. The new legislation demanded that the subsidy percentage increases with the total accumulated consumption of the patient. As the purchase and delivery of medicine could take place at any of the 300 independent pharmacies, this legislation inevitably called for a central on-line database (with all citizens' accumulated purchase of medicine).

During the last 10 years the demand for collaborative services also increased, especially in situations where many professionals (from different service providers) concurrently participate in the treatment of a patient. Telemedicine initiatives are good examples of new care patterns demanding new ICT solutions.

Seen from an ICT-viewpoint the development of infrastructure support from the 80s and the 90s can be divided in

- Establishing and maintaining a secure network for asynchronous exchange of messages and files
- Local ICT-solutions supporting the business and clinical expertise of each actor.

During the last ten years this trend has been supplemented by the need for establishing a number of on-line services supporting specific collaboration processes between actors (one prime example being the medication process).

The second part of this paper describes the implications caused by this.

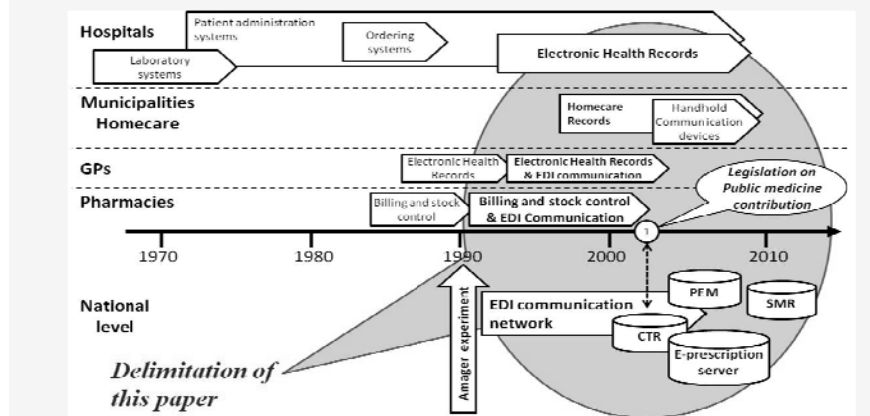


Fig. 2. Steps in ICT development in the healthcare sector in Denmark

3 The Start of a National Health Care Data Network

One of the problems considering the patients' situation as shown in figure 1 is securing effective communication between the involved parties of patient data. This was/is, unfortunately, often missing.

The development of data communication networks and services made it natural in the late 1980s to see digital exchange of data as a possible solution of the emerging data exchange problems in the healthcare sector. The advantages are a.o. that actors receive selected and relevant patient data from other actors without undue delays, that failures in transfer of data between actors could be minimized and that workflows could be made more effective.

The Amager experiment

In 1988 the first step towards this data network was taken. A pharmacist on the island of Amager near Copenhagen realized he had an employee sitting in a telephone boot for many hours per day, receiving telephone-prescriptions from the GPs in the area. On the other hand, the GPs found that the telephone number of the pharmacy was often occupied. The pharmacist was convinced that a better solution would be digital exchange of prescription-data. In 1989 he persuaded The Pharmaceutical Association to take an initiative to assemble the interested parties: The Danish Health and Medicines Authority, The Danish Medical Association, the regional authorities and different suppliers of it-systems and data-communication services. The so-called *Amager Experiment* was created with the purpose of testing the technical possibilities and evaluating the consequences of the electronic data-interchange of prescriptions.

It turned out to be a complicated project due to the following:

- many involved parties with different agendas,
- 4 different GP-systems should communicate with 2 different pharmacy systems which resulted in 8 different interfaces,
- communication standards had to be agreed on and developed,
- data security issues had to be considered and last but not least
- the parties who invested most were not the parties who gained most.

The project started behind schedule in January 1990 but ran quickly into problems. It turned out that the data communication was difficult to realize in practice. The parties could not agree on how to handle failures, and the technical solutions were not interacting as prearranged. To solve the problems an independent consultant was hired as technical project manager.

A considerable number of problems had to be solved. A standard prescription EDI (Electronic Data Interchange) message was created and agreed on, a reliable technical solution was outlined, and systematic testing of interactions between the GP systems and the pharmacy systems was undertaken. It also turned out that there was a need for a new message: an EDI receipt message returned to the GP system in order to secure that the prescription was correctly received in the pharmacy.

The prime success-criteria were that the involved parties could acknowledge the perspective in electronic data interchange and that the security issues could be solved.

After solving many problems the experiment was running almost smoothly by the end of 1990. The results were considered very promising, and it was decided to continue and extend the communication to involve more GPs and pharmacies.

In September 1990 a project evaluation report was presented. It had a number of recommendations specially directed to The Danish Health and Medicines Authority, who had to give the official permission to continue the dissemination of electronic data interchange in the sector. The authority should

- approve data communication of prescriptions between GP systems and pharmacy systems,
- decide on minimum requirements for GP and pharmacy systems before they could be authorized for data communication,
- implement an authorization procedure for systems,
- reexamine the content of the EDI prescription message on the background of the experience gained from the Amager experiment and
- invite to new and more elaborated projects in the area.

Even at this early stage the perspective was emphasized. The Amager Experiment showed the use of open standard EDI- messages as a mean for paperless interchange of medical data between the parties in the healthcare sector and you could catch a glimpse of the vision: A National Health Care Data Network.

The data network experiment in Odder

Based on the results in Amager, where the interchange of prescription data became everyday routine, the county of Århus in 1991 decided to launch a larger project with more actors and more messages involved.

In the town of Odder the project was organized with the following actors, as shown in figure 3: GPs, Hospital departments, the county, the municipality, and the pharmacies.

This was an interesting project because it dealt with a substantial part of the messages in the healthcare sector. In comparison with the connections seen in fig. 1, we already covered a major part of the channels. However it must be noticed that the messages shown with dotted lines were only tested sporadically during the project.

The establishment of the secure communication network also made it possible to exchange text-based secure e-mails between all the parties who participated. On the one hand this made the communication very effective and on the other hand e-mail was used for messages in the interim period where the standard EDI message was not yet finalized and authorized.

What were the benefits for the citizen? This is a natural political question, and in the evaluation report from the project a short story from the daily operation was told as an illustration of the perspective:

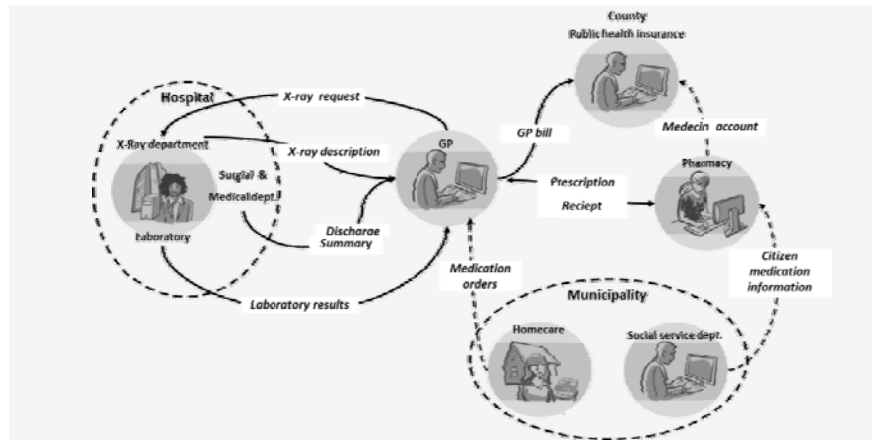


Fig. 3. The Odder experiment - essential electronic messages

A patient in the small city of Malling (near Odder) is seeing his GP in the morning and the GP finds a need for an X-ray examination. The GP sends an EDI X-ray request to the hospital in Odder. The patient drives to the X-ray department and gets his examination according to the request from his GP, which is received in the X-ray department. The X-ray specialist prepares a description of the findings, which is sent as an EDI message to the GP, who receives the message typically half an hour later. If an acute treatment is needed, the GP gets in touch with the patient and the treatment can start only a few hours after his first visit to the GP.

The project started in 1991 and ended in 1993. As a result a number of suggestions for standardized messages were implemented, and it was obvious that the prerequisite for a common network is the mandated use of standardized messages. This gives all vendors the possibility of developing and testing systems with interfaces that can handle the standardized messages. Besides this all the participating actors experienced benefits in administration and decrease in errors.

MedCom²

Later other projects were launched, and at the end of the decade all pharmacies, most GPs and most laboratories were connected to a common data network.

One of the most important developments came as a result of a project in the county of Fyn, the FYNCOM project. This project resulted in the establishment of *MedCom*, a national organization where the Ministry of Health, The Association of Local Governments (KL) and the Association of Counties (ARF) took part. MedCom was in 1994 established as a public-funded, non-profit organization. MedCom facilitates cooperation between authorities, organizations and private firms linked to the Danish

² For the development and documentation of the EDI-messages we refer to www.medcom.dk

healthcare sector. And MedCom ensures the standardization work of EDI messages. MedCom contributes to the development, testing, deployment and quality assurance of electronic communication and information in healthcare in order to support good patient care. MedCom works on the basis of the political objectives and milestones with respect to cross-sector communication and has a unique role as executing agency. MedCom works with focus on supporting efficient operations and incremental expansion of the national health ICT infrastructure, which is needed for a safe and consistent access to relevant data and messages across counties (later regions), municipalities and GPs.

MedCom has until now given great contributions to the development in the area. This is illustrated by the graph below which shows the increase of volume of actual exchange of messages per month.

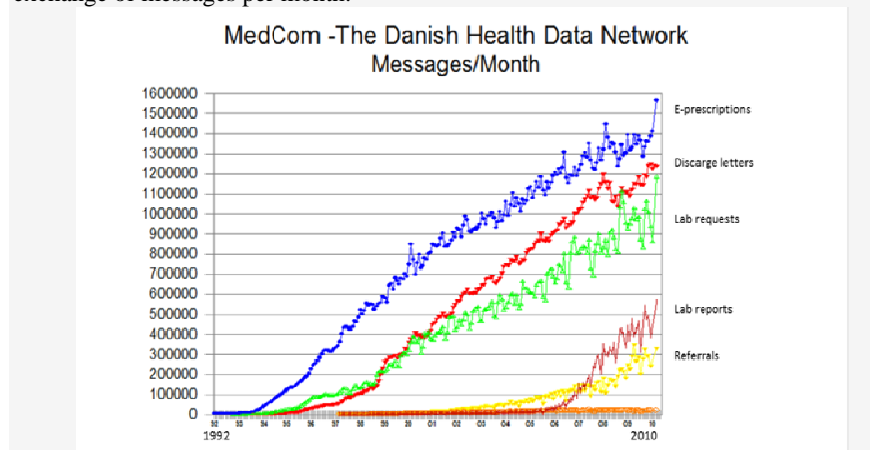


Fig. 4. Increase in volume in message exchanges

4 The Change to Sharing Data instead of Sending Data

The above information exchange-pattern, where independent ICT systems on request or at certain events exchange data with designated partners, is well suited in cases when only bi-lateral communication is needed or few actors are involved, and when they all know each other beforehand (just like exchanging e-mails). But if actors get involved in the patient care without prior notification and instruction from another actor, or if an actor needs actual and up-to-date patient record information, this exchange-pattern proves insufficient.

Increase of message and file exchange between actors will to a certain degree compensate, but will never be a complete solution. Mainly because you will need to develop and maintain many integrations between many ICT systems (“spaghetti-integration”) and you never know where the most actual and newest information is stored. This is illustrated in fig. 5 below.

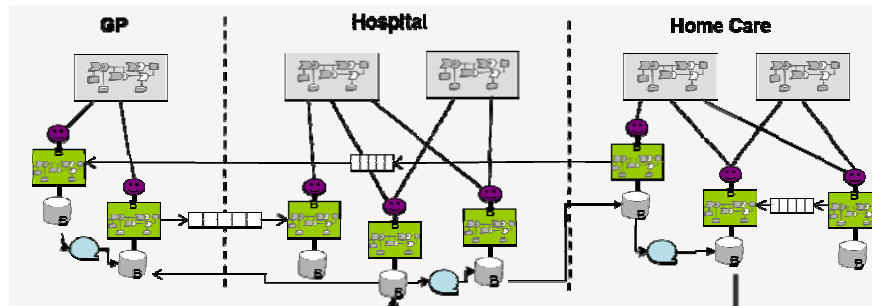


Fig. 5. Mesh-network integrations between many ICT systems

This integration pattern has the following draw-backs:

- Data are pushed in between many applications and systems through EDI messages and FTP file transfers
- All relevant receivers do not necessarily receive the updated data
- Copies of the same data exist in several systems (where is the master/most updated data?)
- Semantic point-to-point connections based on bilateral agreements
- Expensive point-to-point integrations between many ICT-systems

To compensate for this you need a central coordinating ICT system with services, which enables immediate on-line access to updated information. The parallel to projects sites where project members can share documents and information in a controlled manner is very obvious.

However, as previously mentioned, the first step towards a national coordinated system with a centralized on-line database did not occur as a result of cooperation between actors, but was initiated as an effect of national legislation in 1999. All medicine on prescription receives public subsidy, i.e. the patient only pays part of the price of the medicine. The new legislation demanded that the subsidy percentage increases with the total accumulated consumption of the patient. As the purchase and delivery of medicine could take place at any of the 300 independent pharmacies, this legislation inevitably called for a central on-line database (with all citizen's accumulated purchase of medicine).

This legislation paved the road for a number of shared services within the medication area:

- The Medicine profile containing all citizens purchase of prescription medicine.
- E-prescription server as a national on-line service containing all prescriptions and enabling pharmacies to deliver and price medicine correctly
- The shared medicine record (SMR), which is a national service for doctors, nurses, pharmacists, and the citizens.

Figure 6 below illustrates the SMR concept:

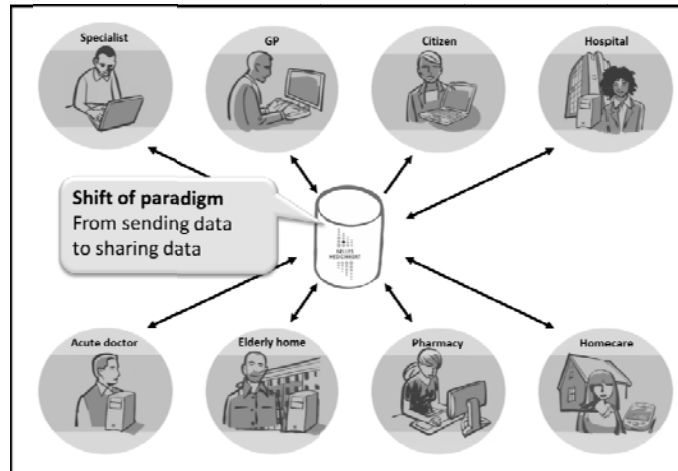


Fig. 6. The SMR: Change from sending patient data to sharing patient data

The basic new concepts of SMR are:

- Shared Medication Record (SMR) contains a patient's current and updated medication
- Provides to healthcare professionals a quick actual electronic overview
- All prescriptions and changes in medication are stored in SMR. SMR is the master database.
- Provides overview for the patient
- Prescriptions are handled by pharmacies through the SMR
- All access to SMR from the actors is done through own ICT system (no additional system needs to be accessed)

During the last 10 years the demand for collaborative services has increased, especially in situations where many professionals (from different service providers) concurrently participate in the treatment of a patient. Telemedicine initiatives are good examples of new care patterns demanding new ICT solutions.

This trend indicates the urgency of sharing healthcare information between the patient and a constantly changing number of healthcare professionals – in a secure way.

Or it is an acknowledgement of the fact that healthcare records belong to the patient and is only shared with professionals if approved by the patient. Patients healthcare records thus will never become an asset of the professionals.

5 Experiences and Knowledge

Looking back on the development of a healthcare data network in Denmark the experiences can be resumed in the following important points:

- Shared infrastructures and services require cooperation and commitment from all parties – it is not necessarily the parties who invest most who get the most outcome!
- EDI messages were well suited for the start: the e-prescription, referrals and lab requests turned out to be great successes!
- EDI messages were well suited where one party sends a message to a known other party and expects an answer, i.e. a dialogue!
- The EDI development was lacking of a common agreed concept model, which could give a unique definition of the elements, agreed by all parties!
- EDI messages are not a solution when many parties need to be informed – and you don't know which party will use which information and when!
- The EDI development and deployment has taken 20 years – based on voluntary participation!

6 References

1. Fischer & Lorenz: *Amagerprojektet, Elektronisk receptoverførsel læge/apotek, Evalueringsrapport*. Internal report in Danish, distributed to all actors in the project. (September 1990)
2. Herbert Jessen: *Værdibaseret it-understøttelse inden for sundhedsområdet*. printed Børsen Forum: it-håndbogen. (2013)