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IT solutions in a centrally organised mammography screening in Norway

Per Marcus Ottestad
The Cancer Registry of Norway, Institute for epidemiological cancer research
Montebello, N-0310 Oslo

Abstract. The aim with this paper is to explain the IT-solutions in a centrally organised mammography screening project in Norway. All of the major participants in the project are connected together in the same network (ISDN). Sending and receiving data is automatically taken care of with a replication server. In this way very sensitive medical data are being transferred via telecommunications among each participant. To secure the information that are being transferred an encryption/decryption unit is being used.

1. Introduction

In 1992 the Ministry of Health and Social Affairs decided to start organised mammography screening in four pilot counties; Akershus, Oslo, Hordaland and Rogaland. Women between 50 and 69 years old will be invited every second year. These four pilot counties contain about 160 000 women, 35 percent of the total female population in the age of 50 to 69 years in Norway.

2. Organisation

It was decided to give the project status as a pilot project in order to obtain the best organisation model and the best professional quality that will be of value to the future work within mammography screening in Norway. The main goal with the Norwegian programme is to achieve a mortality reduction of 30 percent among the women being tested, an effect equal in magnitude to the results from Sweden [1].

The screening will be done at stationary units in the big cities (Oslo, Bergen, Stavanger), while mobile buses will be used in the countryside.

In order to control the fulfilment of the project aims there has been given priority to the work of defining quality goals of the screening [2]. The data that is needed in order to control the achievement of the goals will be recorded in a central database at the Cancer Registry of Norway. There will be an identical and a complete copy of regional data in every pilot county. In addition to these data some epidemiological information of the women invited to the screening is registered. This information will be used in future cancer research.

The project group soon became aware of the fact that the registration of information would require very well organised routines.

A registration system based exclusively on paper would have been of little effect and was therefore never considered as an alternative. There were sceptical voices to the choice of using new and complex technology. On the other hand, the fact that the system had to be made from scratch, offered an unique opportunity to build a modern system based on a new technological architecture. A client/server model was chosen. Database replication are used in the exchange of data.

3. System description

The main participants in the project are:

- The Cancer Registry of Norway - it has the main responsibility for the project as well as the IT solutions. The main database is located with the Registry, in Oslo.
- The National Health Screening Service - which is responsible for scheduling appointments in every pilot county, and to distribute letters to the women.
- Mammography centres - one in each pilot county. Change of appointments and reading of the mammograms are taken care of here. Each centre is also responsible of the handling of letters to women with positive findings.
- The screening unit - each county has two screening units, either stationary or mobile, where the actual screening is done. Information that might be relevant to the radiologist are registered here.

All participants (except the screening units) are connected in one network (by ISDN). This solution simplifies the exchange of information, but it requires a very safe system for data security. A technical overview of the IT-system is illustrated in figure 1.

The National Health Screening Service give appointments to the women that fulfils criteria for residence and age. An invitation letter is sent from The National Health Screening Service directly to the invited women together with a questionnaire form. The woman will return a complete version of this form on her visit to the screening unit. The form contain epidemiological data, and are returned to the Cancer Registry where the forms are scanned and saved into the main database by means of optical character recognition technology.

After receiving information from the National Health Screening Service concerning the invitation, the Cancer Registry will distribute invitation data to the respective counties. All participants can call their local centre if they need to change appointment-time. All stationary units use ordinary telephone lines with a modem. The mobile units use GSM mobile telephone communication. Each centre and screening unit have their own X.400 post-box. The mammography centre will send the time schedule list for the next day to the screening unit one day in advance. This is done by file transferring to the unit's post-box using a mailing application. The time schedule list is then imported into the registry program at the screening unit. At the end of every day, recorded information is sent back to the centre in the same manner.

When the radiologists are reading the mammograms at mammography centre, the information collected at the screening unit is available for the application the radiologists are using.

When the results are ready, they are sent back to The Cancer Registry. Every woman that have a negative result gets a letter stating that nothing was found. This letter is sent no later than ten days after the screening took place. The local mammography centre is responsible for recalling every woman with positive findings.

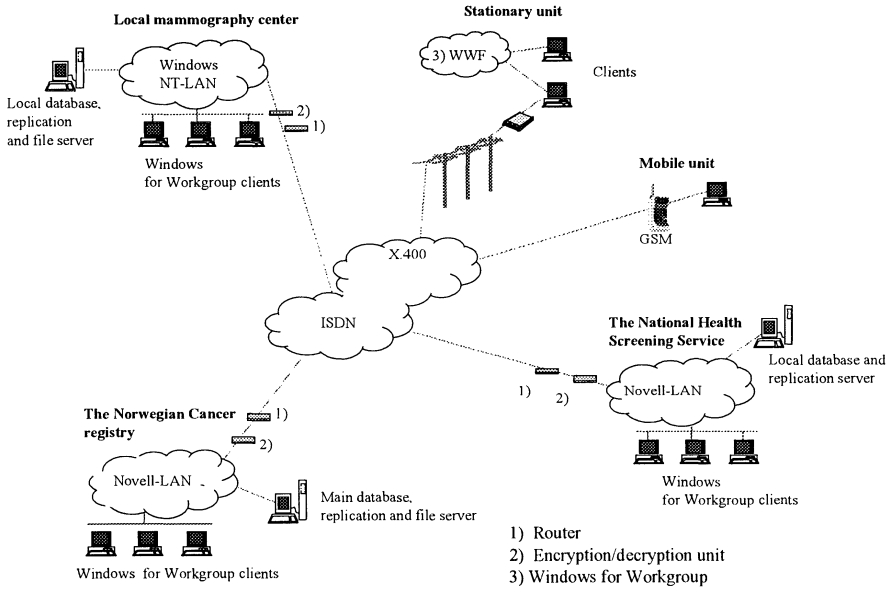

Figure 1: A technical overview of the IT-system

4. Human - Computer Interaction

A risk connected with the introduction of data systems with high complexity is that end-users may not have the ability to fully take advantage of the system. It is not enough to build a system that meets all of the technical requirements, it must also satisfy end-user's needs. Among the participants in this project, just a few had any prior experience with using PC in their daily work.

With this in mind, large resources where used in the early planning phase, to make each application so user friendly as possible [3]. Representatives of the end-users participated in this work. The goal was to promote a positivė attitude among those who actually would run the system and avoid a sort of technical scepticism.

5. Information security

Data-systems that involves medical information about persons, require a very good security policy. The following issues were considered when deciding the security level:

- Confidentiality - impossible for outsiders to access data being transferred
- Integrity - protection against unauthorised change of data

- Access control - prevent unauthorised attempts to get access to the local net
- No bottlenecks in the data traffic

The project had to seek permission both to register and send sensitive data. To fully secure data that are sent from one location to an other, a encryption unit, (NX1000) invented by the Norwegian military and Norwegian Telecom, is being used. When transferring, data always go through the encryption unit before it is sent to another location where it is being decrypted with the technology.

Another method is used to secure the data transfer between the local mammography centre and the screening units. The data security solution used on the ISDN network is too expensive when dealing with the small data volumes that pass between each centre and it's screening units. The data files transferred between the centre and the units are encrypted with a program called PGP (Pretty Good Privacy). This program use a highly secure algorithm [4], a mathematical formula that converts the information into something that is useless to other people. The algorithm works in conjunction with a special code called a key. The encrypted data cannot be read until it has been decrypted, using the same key.

6. Conclusion

The pilot project started in October 1995. So far the data-systems seem to work to everybodys satisfaction. Part of the success is explained by:

- The work that was done in the early planning phase concerning human - machine interaction, securing support from the users.
- The use of data-replication for sending/retrieving data among the main participants. It would not have been possible to build this kind of system so fast if more traditional solutions had been used. Also reliable security solutions have kept us out of the newspapers.

Two other important aspects of the IT -solutions are:

- With one main database for the entire project it is easy to control the quality of the registered data and to make correct research reports.
- Finally - since each pilot county has their own identical copy of the main database (only data concerning this particular county), they have the possibility of using the data for their own statistical purposes. Another advantage with this solution is that the local system will continue to work, if we get system or hardware failure on the main database.

References

1. Nyström L, Rutquist LE, Wall S, Lindgren A, Lindquist M, Rydéd S et al. Breast cancer screening: overview of Swedish randomised pilots. Lancet 1993; 341: 973-8
2. Pilot project with mammography. Quality manual. Oslo: The Cancer Registry of Norway, 1995
3. Thimbleby Harold. User Interface Design. ACM Press, 1990.
4. Kent Peter. PGP Companion. Ventana Press, 1995