NIDOK - a data management system for kidney transplant data

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0.) Abstract

Before, during and after a kidney-transplantation a lot of data come up at different clinical departments. With our system, named NIDOK, all those data can be captured at the place they are coming from enabling at the same time all other departments to use this information as well.

Furthermore the necessary data exchange with the Eurotransplant Centre in Leiden (Netherlands) that keeps an international waiting list and supports the distribution of organs is implemented. Registration for the waiting-list and all other actualisation of data in Leiden is done simultaneously with the entry of the data and carried out by the system itself. Moreover it is possible to extract data for scientific analysis.

The system was introduced in March 1993 and was welcomed by staff at all levels. It proofed to be able to decrease workload sensibly. Additionally it brought on a big improvement in data quality.

1.) Introduction

Transplantation, especially kidney transplantation, has developed into the treatment of choice with serious kidney diseases. This led not only to a rapid increase in transplant operations during the last years, but also to increased workload in the organisational and administrative sector.

During a transplantation a recipient receives an organ from a donor. Figure 1 illustrates how a patient is dialysed while he is on a renal transplant waiting list and how he can return to the dialysis unit if the graft is rejected. Whenever a potential donor dies, a recipient matching him according to immunologic, medical and organisational aspects is chosen.

To facilitate this task, the general hospital of Vienna is participating in the Eurotransplant Foundation in Leiden (Netherlands), an organisation that keeps an international waiting-list and supports the distribution of grafts. To be able to allocate the right organs to the right patients all data concerning the recipient as well as the donor have to be present. Until now data was sent to Leiden per Fax or Telephone.

It was decided to develop a central information system that would contain all the transplantation data and make them available for the various departments involved in the transplantation process. Furthermore the data exchange with the Eurotransplant Centre in Leiden should be managed by the new system.
2.) What was needed

Transplanting a kidney is a process more than one department is involved in. Recipients are first administered at the Department of Nephrology. The laboratory determines the blood group and HLA-Type. Donors are registered at the Transplant Centre and transplantations take place at the Department of Surgery. Children are treated at the department of Paediatrics.

Besides, relevant data for kidney-transplantations split up in time-related items such as weight and height and static items like date of birth or sex. Figure 2 shows the different kinds of data captured at the different departments.

With the new system entering the data at the place they come up should be made possible. On the one hand should every department be able to view all the data, on the other hand should departments only be entitled to enter or change those data they are responsible for. The Department of Nephrology, for example, should be able to register a recipient, but not a donor. Nevertheless it should have the possibility to get some information about the donor of the kidney their recipient got transplanted.

As a second point the system should handle the communication with the Eurotransplant Centre in Leiden. As soon as the data is entered it should be transmitted to Leiden without further assistance from the user. Similarly reading the answer from Leiden should be easy as well.

3.) What we developed

We realised the system on a 3090 IBM Mainframe under the Operating System CMS. Users are connected via terminal or terminal-emulation an IBM PS/2 or Apple Macintosh.
<table>
<thead>
<tr>
<th>Recipient:</th>
<th>- basic data (personal and medical data) (\text{(Neph.)})</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- data of quarterly check-up (\text{(Nephrology)})</td>
</tr>
<tr>
<td></td>
<td>- Blood-group and HLA-Type (\text{(Laboratory)})</td>
</tr>
<tr>
<td>Donor:</td>
<td>- basic data (personal, medical</td>
</tr>
<tr>
<td></td>
<td>- and organisational) (\text{(Surgery)})</td>
</tr>
<tr>
<td></td>
<td>- HLA-Type (\text{(Laboratory)})</td>
</tr>
<tr>
<td>Transplantation:</td>
<td>- data of the transplantation (\text{(Surgery)})</td>
</tr>
<tr>
<td></td>
<td>- Follow-up (\text{(Nephrology)})</td>
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**Figure 2:** Different kind of data captured at the different departments

The User-Interface and all data manipulations are written in SAS*, especially SAS/AF* and SAS/FSP* with Screen Control Language. Data is stored in a SQL Database to make it available for more than one CMS machine and is accessed through SAS/ACCESS* Interface to SQL/DS Data Management Software. Data transmission to Leiden works over Datex-P and a KERMIT-Protocol. File Transfer and Manipulation is carried out by TNET, a product of IBM Heidelberg.

Because the Laboratory staff has a PC-based information system of their own, they do not enter data directly into a CMS machine, but send it via TCP/IP. An administrator looks after the system and tracks down errors if necessary. See Figure 3 for an overall view of NIDOK.

When the user invokes NIDOK, he may choose one of four main items in the main menu. These are:

- Viewing Data
- Entering and Updating Data
- Downloading Data
- Reading Answers from Leiden

Within the first item, **Viewing Data**, the principle that every user may always view every kind of data was realised. To facilitate finding the right data and the right patients predefined collectives of patients (such as the waiting-list) and data (such as time-related data) may be chosen. Powerful searching commands are available through pull down-menus (SAS SEARCH command with predefined strings, WHERE commands, FIND command, predefined Pmenus).
The second item, **Entering and Updating Data**, is used for data entry and transmission to Leiden. Every department may change or enter only those data it is responsible for. This was accomplished by SQL grants and appropriate use of SAS access and view descriptors. Prior to updating a patient he has to be identified. Several possibilities to identify a patient are available (ET-Number, Internal Identification-Number or combination of First name, Name and Date of birth). As soon as all data are entered and successfully saved, a transmission file is built and sent to Eurotransplant Foundation in Leiden. Then an appropriate message is displayed for the user.

When we implemented this part of the system we spent a lot of time on making the system secure and error-resistant. Efforts were made to avoid errors in data by large-scale cross-checks. Designing the interface as user-friendly and easy to use as possible was part of those efforts.

A great advantage when using SAS is that data is available in SAS and can be analysed very easily with all the elaborated procedures available in the SAS System. Using the third item, **Downloading Data**, the user may extract the data from the SQL Database into a SAS Dataset and may go right into analysing his data instead of having to do cumbersome conversions into foreign dataset formats.
In the Vienna General Hospital a system called WAMASTAT is used widely, which provides a kind of interface for using the SAS System. This system was built by our department long before SAS/ASSIST was available and is used throughout the hospital by many clinicians and other medical staff.

Everytime a patient is registered in Leiden a registration number, the so called Eurotransplant Number, is returned. The answer to an update is just an acknowledgement. With the last item, Reading answers from Leiden, those answers are read in and checked for errors. The Eurotransplant Numbers are stored in the database.

4. Why we used SAS

One of our primary goals when creating NIDOK was to make it as easy to use and as user-friendly as possible. Because end-users have already experience with PC systems, they are used to the features common on PC software, like use of the mouse, push-buttons or pull-down-menus. Working on a mainframe the worst problem is that everything "looks so ugly" and is difficult to use.

So it really is a relief that since release 6.06 SAS provides features usually only known on PC systems on a mainframe, such as pull down menus or push buttons. We keenly took the opportunity to build our own pmenus and selection-lists, to facilitate data-entry with push-buttons or choice-groups and to use the various features of Screen Control Language. Those benefits together with a careful coordination of paper forms and screens made NIDOK a big success with the users.

With SAS/ACCESS software we are able to benefit from two systems, SAS and SQL/DS. Storing data in SQL/DS allows us to share data and access it concurrently. Using SAS for the user-interface provided us with the advantages mentioned above. Although we had some troubles in the beginning, we managed to establish a multi-user information system.

A very important part of NIDOK is the transmission of files to Leiden. We bought a product of IBM Heidelberg, TNET, for that purpose. SAS is so flexible that it was no problem for us to integrate this communication software, that handles the sending and receiving of files, into our system. At this time it is the possibility to use commands of the underlying operating system that is so valueable. The conversion of data into the transmission format was no problem either. It was accomplished with SAS PUT statements.

Another advantage in using SAS are the powerful statistical tools. The data gathered for organisational and medical matters are often used for scientific purposes as well and with SAS data exploration and analysis is at hand.

Last but not least SAS has been in use in our department for over ten years now so we, the developers, as well as the users have experience in using SAS and do not have to learn something completely new.

5. Conclusion

The system NIDOK is in use now in two departments, the department of Nephrology and the department of Pediatrics. It was welcomed by staff at all levels. They find it easy to use and practical to work with. Modules for the laboratory and the surgery are still under development, but are expected to be finished by the end of the year.
Introducing the system decreased the workload sensibly, not only because the system takes over the task of storing and sending the data, but also because it brought up some organisational changes. Competence and responsibility are divided now clearly between the departments. This improves not only working conditions for the staff, but also makes it easier to maintain a high standard of data. Everyone involved recognizes a big improvement in data quality. Less errors occur and less data are missing.

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