Uniform Pacemaker and ICD Information System in The Netherlands

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Abstract

In the Netherlands the Central Pacemaker Patient Registry (CPPR) collects information of pacemaker and ICD (Implantable Cardio Defibrillator) patients from all 109 Dutch hospitals. Many pacemaker clinics are using a computer to store their implant and follow-up data in a database. Because the devices are getting more and more complex more clinical data is needed for an optimal use of the device. From 1989 databases are developed by several pacemaker industries and some clinics use own developed databases. When using these databases you depend on individual persons for support and update of the database. In order to improve the accuracy of the received data and to ensure continuity a uniform pacemaker and ICD information system is developed where data is checked after which it is sent to the central registry by e-mail and where support is guaranteed by the NPRF.

1. Introduction

The Central Pacemaker Patient Registry in The Netherlands exists since 1976. The data collected is described on the European Pacemaker Patient Identification Card (1). Since 1979 the registry is computerized (2). At this moment the database contains information on more than 98.500 patients, 122.000 pacemakers, 2.500 ICD's and 139.500 leads. The information from all implanting centers is received either electronically by modem or e-mail (60% of the clinics and 70% of the implants) and processed semi-automatically or on paper and copied by hand. The hospitals that transmit their cumulative information by modem or e-mail have their own local database. The communication with the central registry is set up with communication software according to the state of art in 1989 (modem) or as an attachment (e-mail). This approach approved to be supreme to the paper based communication where the necessary copying of information by hand introduces the majority of errors. A validation study (3) on the data of the CPPR in 1995 showed that although patients could be traced in 100% of all requests, the database searches were not that successful in case of pacemaker or lead recalls, especially when ranges of serial numbers were concerned.

These local databases however showed some drawbacks. They allowed free text entry for the pacemaker models (existing or non-existing), manufacturers, general practitioners. Also they are not able to send the data as requested from the EURID protocol for ICD's, etc. The new pacemakers and ICD's have more programmable features than the old ones (figure 1). These new features cannot be added to the database because the database is no longer supported by the company that developed it.

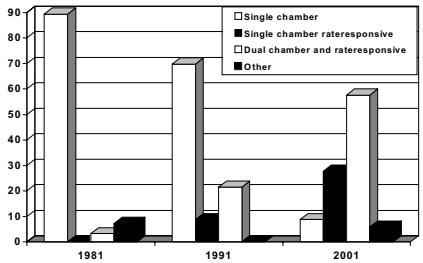


Figure 1. Mode (%) at implant in 1981-1991-2001

Above described observations led us to start a project to improve the accuracy of the centrally stored data and to ensure the continuity of the information system by developing a nationwide used local working information system.

2. Methods

Several software packages were evaluated to serve as the base of this new system. It had to be easy to work with for all the clinics and a conversion of data from the "old" system had to be an option. The costs should be acceptable for the Dutch Pacemaker Registry Foundation.

This evaluation led to the use of GRIT-PM, an information system developed in the University Hospital in Groningen for the pacemaker clinic within the Cardiology department. The GRIT-PM had to be disconnected from the local database and some tools mentioned below had to be added. The new system is now called GRIT-SPRN.

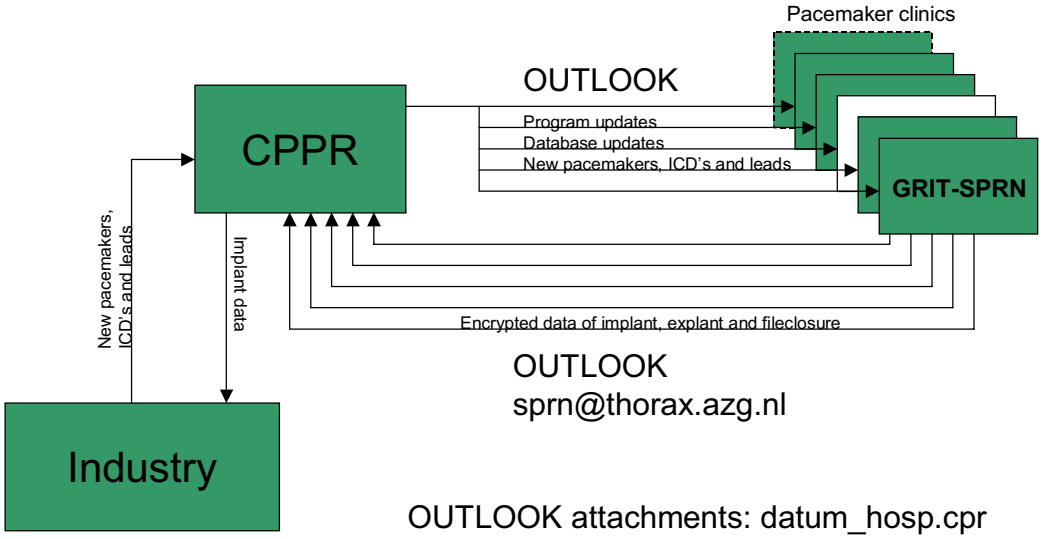


Figure 2. Flow chart of communication pathways

The first idea to store only data important for the central database turned out to be not acceptable for technicians to use the information system. It was indicated that more data storage was needed, which would be also an addition to the "old" system.

Of great importance is that the information system is independent from the industry and no costs have to be made by the clinics, except hardware.

Many items to be entered are stored in check files enabling the user to just point with the mouse to a predefined list. These lists are managed centrally and automatically updated whenever needed. The lists concern a variety of coded data types like symptoms, names of pacemaker companies, pacemaker types, pacing modes, cause of explantation, ECG definitions, patient complaints, etc. The CPPR is depending on the information of the industry about the new pacemaker types. E-mail will be used to update the program in all the clinics (figure 2). Technical information about the pacemaker and lead will be received from the STIMRO database, a connection that will be making soon.

All the other entered information is thoroughly checked whenever possible on:

- Syntax (like dates, names, etc.)
- Possibility (like implantation dates before 1955)
- Plausibility (like implantation date before date of birth)

The information system, GRIT-SPRN, has been developed in Visual Foxpro 6.0 under Windows 95 containing the following screens:

- Patient data – general data, including general practitioner, cardiologist
- Operation – implanted and explanted pacemakers, ICD's and leads and measurements during the procedure
- Follow-up – settings, measurement and diagnostics
- Report –standard reports for cardiologist or general practitioner in Word, made by the clinic
- Agenda –appointments in the pacemaker clinic for follow-up
- Statistics - descriptive statistical tables that can be exported to Excel
- Communication – sending data to the central database

Follow-up data of the last visit is copied to the next visit. Only data that changed since the last visit have to be typed in. You can also use the graphics tool of MS Graph to make an image of the progress of a certain item. There is also a special page where every hospital can fill in their own extra information that is not yet in

the system. In this way the system is made flexible for each hospital.

Every item from the information system can be selected for use in different reports that are exported to MS Word.

The option Statistics can be used to export a selection of data to an MS Excel file where major statistics can be done.

At any time data can be send to the CPPR by using the Communication option. At this moment only the data of implant, explant and file-closure are collected.

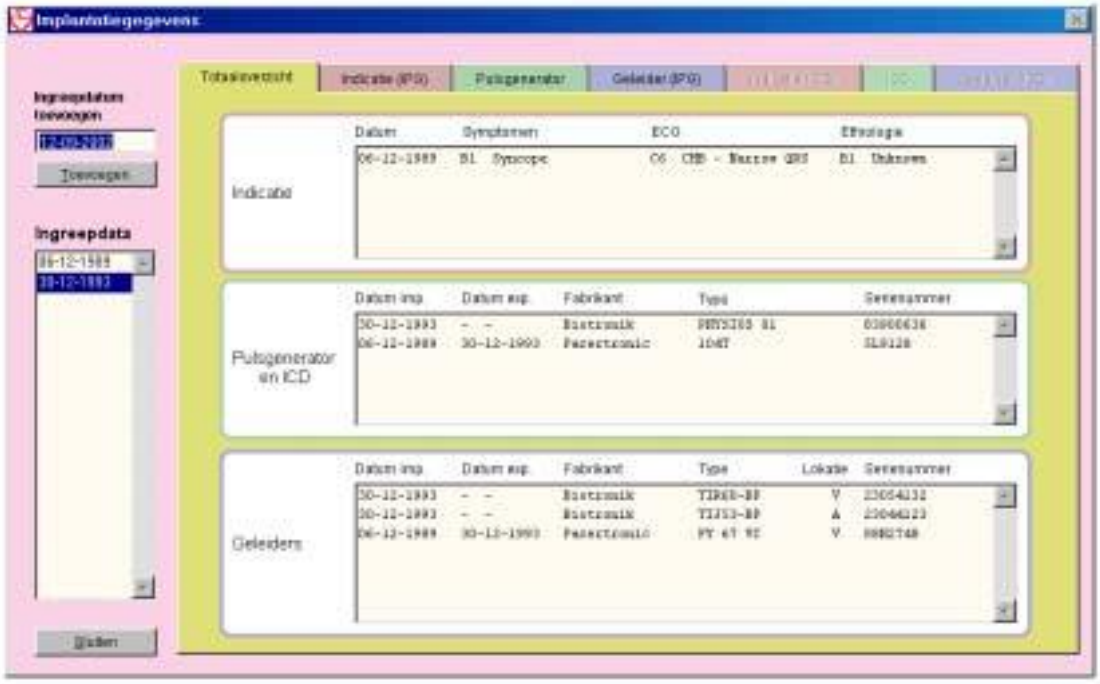
It will be easy to enlarge the centrally collected data for study purposes. The information system is using MS Outlook to send the file to the CPPR. The file is encrypted to protect the information of the patient against unauthorized usage.

The figures on page 3 and 4 are examples of the operation screen and of the follow-up screen.

The information system is still constantly changing but one can say that the bases for the information system is set now and that 75% of the programming has been done. A group of technicians is supporting the development of the information system by giving feedback about the needed storage of data.. It is obvious that centrally managed check lists are important for the continuity and for the implementation of new items.

The information system can be used within a network environment. This means an automated daily back-up by the system manager, and also that the system can be used at different locations. To protect the data for unauthorized use a password is needed and also different levels of users are possible.

The quality of the data did improve as was anticipated. Only minor double data checking is needed and less corrections have to be made. As in



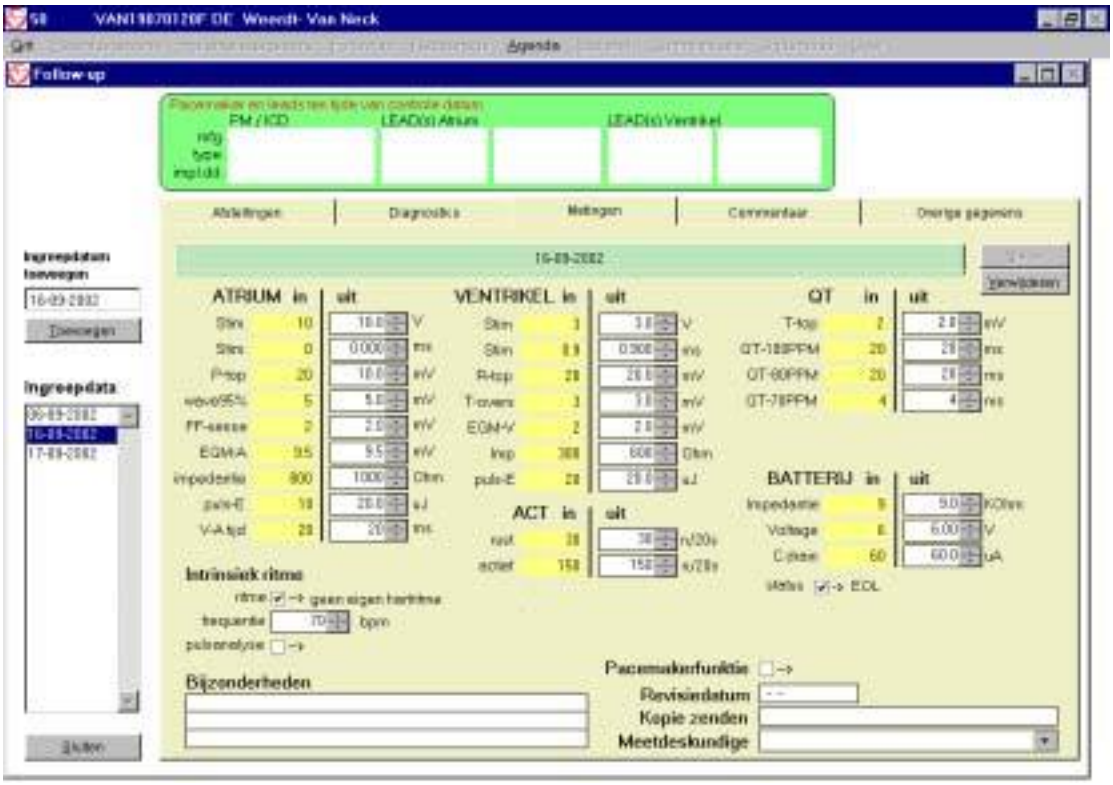
1997 was shown 95% of the data entered was correct when checked on serial number of the pacemaker we now believe that this percentage shall be between 97 and 98%.

3. Results

At this moment 15 clinics are using the information system and are sending the data to the central registry by e-mail. Many technicians are waiting for the conversion of their “old” data before using the system. This means that the conversion is a very important issue at this moment. Technicians are aware that the conversion can only be done with their help and that not all data can be converted. A group of users of the “old” database is supporting the conversion.

4. Future

Pacemakers as well as ICD’s have many options that can be programmed depending on the needs of the patient. This means that not only pacemaker data are needed at the clinic but also more clinical data like use of medication.



New developments within the pacemaker and ICD will ask for more data to be collected. Nowadays for instance more than 2 leads can be connected to the pacemaker. For this a new set-up of the information system is also requested.

The Dutch pacemaker industries are very enthusiastic about a standardized information system used in all the clinics. They support it by informing the cardiologists and technicians about its development and by financial support. Importing data directly from the programmer is the next thing to do.

In the Netherlands a major study (4) is starting to investigate the efficiency of the follow-up within the pacemaker clinics. The new information system could be a very important tool to collect the needed information.

Hospitals have their own information system where the general data of the patient is collected. The connection between that system and GRIT-SPRN has been set-up. This avoids double data-entry and the possibility of failures in typing.

When the conversion of the first database is finished the majority of the clinics will start using the information system. In the mean time the information from the support group has to be added to the information system.

At this moment the information system is also used in Bosnia Herzegovina and the Ukrainian, where the system will be used for the central registry as well as for the local pacemaker clinics.

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