Regional and International Integrated Telemedicine Network for Organ Transplant (HC 4028 & IN 4028 European Commission DGXIII)


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ABSTRACT
A substantial portion of future medical practice will depend greatly on improved collaboration between the providers throughout the healthcare sector, and effective sharing of data and expertise by different healthcare professionals. In organ transplant it is a rule, donor organs are matched to recipients via national or multinational organ-sharing organizations. Only through close co-operation between transplant surgeons, immunologists, nephrologists, pathologists, radiologists and other physicians could one increase the efficiency of organ transplantation. Information technology (IT) has become an inevitable and inherent part of transplantation medicine. The RETRANSPANT project interfaces and integrates IT from the European Union Fourth Framework projects to support the development of regional organ transplant information networks in Central Europe.

INTRODUCTION
Medical informatics can play a major role in facilitating the integration of health care. Patient data may be delivered from a number of different facilities within the community by different health and social care professionals. It is important that health care professionals at one location have access to information held at other facilities in a transparent way [1].

At the European Council meeting in Corfou, June 1994, the heads of state and government of the European Union discussed a report entitled, "Europe and the global information society" known as the 'Bangemann report," prepared by a group of high-level representatives of the information and communication technology industry, operators and users. This report urges the Heads of State and governments to adopt an operational program of actions, to make sure that Europe can actively and rapidly progress into the information society and fully benefit from the opportunities which are offered by this evolution [2].

A number of decision support tools are already in place in health care environments and their utilization is expected to grow steadily with the development of medical informatics [3]. Teleconsultation is a consultation between two or more physicians about the diagnostic work-up and therapeutic strategy in the treatment of an individual case, by means of modern telematics. As a result of more complex therapeutic strategies and legally defined formal requirements, the need for teleconsultation is expected to increase significantly in the future. Rapid technical improvements in telematics will progressively facilitate the practical performance of teleconsultation (based upon an Integrated Services on Digital Networks (ISDN) network in the beginning, later on by the use of a national health network [4]. Asynchronous (based on Internet E-Mail) and synchronous (based on ISDN-mediated videoconferencing tools) types of teleconsultations are already realized worldwide [5]. An Electronic Medical Record (EMR), in the form of an ID card, is rapidly becoming the standard of hospitals and clinics. Storing archival medical data on such ID cards will be highly advantageous. Computer interrogation of
the EMR can be done very quickly [6]. The solution of the interoperability problem caused by different equipment from different suppliers within such a network will be a major task, the solution for which is in progress [7].

Organ and bone marrow transplantation is a complex procedure. The consequence of this complex situation is that effective transplantation medicine is not possible without well functioning information technology and telecommunications technology. It has become an inevitable and inherent part of transplantation medicine. Nevertheless, there are many difficulties in applying transplantation information technology in different countries.

BACKGROUND
The overall environment of medical Electronic Data Interchange (EDI) application is extremely heterogeneous, complex and quickly evolving. Difficulties arise due to the high number of standardized message types required, the specificity of the message contents and to the number of message-syntax currently in use [8].

In organ transplant, Critical Care environments (e.g. Intensive Care Units, Anesthesia Departments, Postoperative Care Units,) are specifically set up to enable application of significant resources in terms of both equipment and personnel. These environments can account for more than thirty percent of hospital expenditure during transplantation. It is therefore important that these growing expenses are monitored and contained. Critical Care departmental systems and the electronic data emanating from them must be compatible and transferable in time and space throughout Europe and beyond. These systems must be open to the healthcare information space while adhering to appropriate data transfer and security standards [9,10].

Most recently, major companies have moved to standardizing equipment and varying software in order to accommodate specific management and images from different modalities. The natural development from this situation is to link several devices and modalities to the generic workstation and make it multi-modal [11].

Technological advances of recent years have had a particularly strong impact in the field of medical imaging, where film radiographic techniques are gradually being replaced by digital imaging techniques. This has provided an impetus to the development of medical information systems, which supports the digital storage, retrieval, analysis and transmission of multimedia patients records. New information and telecommunications technologies are currently used to enhance the capabilities of all medical imaging modalities and to provide added-value services to the health care community, with an aim toward improving the delivery of health care and ultimately patient outcome.

Telemedicine can be defined as a set of added-value medical informatics services, implemented upon an advanced telecommunications infrastructure and supported by different information technologies and related applications.

Telepathology is an imaging modality with a microscope, a video camera and a framegrabber. Pathologists can retrieve digital images ("secondary capture" images) in accordance with Digital Imaging and Communications in Medicine (DICOM). In teleradiology the image sources can be digital or conventional. Digital images are produced by ultrasound, CT, MRI, angiography, fluoroscopy, whereas x-ray radiographs produce conventional images. There are several methods for the digitization of conventional x-rays: a camera on a stick, a film digitizer, and a frame grabber. The method that provides the digital image of best quality is the film digitizer. Today, there are two types of film digitizers in the market: laser digitizers and CCD digitizers.

The most important security services are those of access control, authentication, data confidentiality and non-repudiation services. In the main, these services are based on encryption mechanisms (RSA, DES) and smart cards. Smart cards, which both carry the keys for the asymmetric encryption and maintain the capability of carrying out the encryption, are among the most sophisticated devices in the field. Smart cards have the advantage that the secret key is never available external from the card, and thus never disclosed. The experiences learned from DIABCARD have provided a basis for broader application including extension to other chronic diseases. Three main groups of chronic disorders seem especially suitable: Cardiovascular Diseases, Chronic Renal Failure, Cancer Diseases [12].

The widespread communication networks available in Europe include X.25, the telephone network, Asynchronous Transfer Mode (ATM) and ISDN. ATM is not yet available as a Europe-wide commercial service.

The RETRANSLANT project aims to facilitate and realize introduction of information technology in national and regional networks in Central Europe. It is obvious that such activity is useful for both parties, i.e. the EC and CEEC. Any potential donor in the CEEC countries may become matched to an EC patient and vice versa.

METHODS

Recipient – Donor Selection Program
Tissue groups are known as HLA (Human Leukocyte Antigen) groups. All cells in the body carry HLA characteristics, but the HLA characteristics are most easily determined from the white blood cells. Like the blood groups, HLA groups are hereditary and are passed on from parent to child. However, in contrast to the major blood groups, the HLA system consists of a large number of sub-groups that occur in all sorts of combinations. Therefore, the chance of two people possessing exactly the same HLA characteristics is very small, and finding a suitable recipient for a donor organ is therefore not a simple task. For that reason, RETRANSLANT project participants will develop medical informatics tools to enable the selection from a large pool of waiting patients the most suitable recipient for every donor organ that becomes available.
The Patient Waiting List (PWL) is created by data, obtained from all potential recipients, stored in a central computerized file or in a network of computerized files (distributed list). The PWL includes such items as blood group, tissue type, cause of illness, clinical urgency and the hospital where the patient is being treated.

As soon as a donor becomes available in one of the participating regions the tissue-typing laboratory closest to the donor's hospital performs blood and tissue group analyses on the donor. This information enables selection of potential recipients to begin. Selection criteria depend on the organ required. For a renal transplant the blood group, the tissue type, the clinical urgency and the length of time on the waiting list are used as basic criteria. In addition, each organ requires special criteria. In the case of the liver or heart, for instance, the dimensions of the organ are important.

The National Institute of Hematology and Immunology, Budapest, Hungary, developed the SELECT 4 recipient-donor matching software for the ITNICT project (EC DGXIII COP-166). Menu driven criteria enables the user to standardize the protocol and the process in all participating organizations.

**Dialysis and Transplant card**

The primary task in the RETRANSPLANT project, concerning the smart card technology, is the provision of smart cards to every patient that undergoes dialysis or is registered on the waiting list for an organ. This task involves more than 3,500 patients in Hungary and Slovenia. The smart card contains personal identification information and some emergency or crucial medical information such as allergies, blood group and HLA groups. The smart card may be used as a management and communication tool providing identification information about the patient (Master Patient Index concept) and as an additional data storage medium maintaining the medical information discussed above.

A card reader reads the card and provides access to the Electronic Health Record (EHIR) system. The card owner, possibly a patient on a transplantation waiting list or a physician, enters his personal identification number (PIN) to the card reader enabling access to the Regional or International Transplant Networks. BULL S.A. (France) provided the prototype Smart Cards, the Card Readers and the required software modules.

**Electronic Health Record**

CrossWay (Integrated Care Systems France-ICSF) is one of the leading electronic medical record products in France for hospital settings. It has been deployed in about 30 sites. A major advantage of CrossWay is that it is designed for “horizontal deployment” across care units of a hospital, thereby facilitating the communication and co-ordination between the care units and the examination departments of the hospital. This Hospital Information System (HIS) contains standardized codes and information about diagnoses (ICD 10), drugs, procedures, investigations, laboratory tests etc. CrossWay includes mailing support for EDI that can be used to transfer information about the patients from one health care facility to another.

RETRANSPLANT participants have considered use of XML (eXtensible Markup Language) as recommended in the EHCRA pre-standard (Dec 98) of the CEN TC 251 and have selected the DPWeb Electronic Patient Record manufactured by ICFS, France.

XML is a simplified form of the SGML (Standard Generalized Markup Language) standard and designed to increase processing effectiveness. XML is based on a decade of experience with SGML and HTML (Hyper Text Markup Language). XML is likely to be the next market standard for the web, far more powerful, general and flexible than HTML.

The DPWeb application was conceived to answer the need of medical records shared by care networks established around pathology. This application allows formalizing the care plan of the patient as well as an explicit follow-up of multidisciplinary dialogues, and may be used to consult or to update a patient record via the Internet. Originally DPWeb was designed to answer the need of shared electronic medical records for oncology networks.

DPWeb is an application developed with the Internet application dynamic generator ColdFusion (editor Allaire). The patient architecture of this electronic medical record, common to CrossWay-Ville, follows the EHCRA European recommendation, which aims to improve the possibility of exchange and sharing of medical information. A MICROSOFT COM (Component Object Model) implements the middleware of this medical record server as well as relational database Interbases (Editor Borland/Imprise).

The forms for data entry and data display as well as the medical guidelines are formalized with XML files. The presentation of form adopts the new XSL standard which enriches the standard XML. The use of the XML technology facilitates the possibility of evolution and of data interchange of the information systems. With this approach modifications or addition of new forms do not require one to modify the application but simply to enrich the parameter setting by the addition of new XML and Style Sheet Language (XSL) files.

Technology used:

- A relational database, at present Interbase, with provisional evolution towards Oracle 8i RDBMS.
- Business middleware, implementing services that deal with core patient data and classes (read/update).
- Thesaurus to standardize the collection of information.
- Computerized medical practices and guidelines support.
- Flexibility of the EHCRA architecture guarantees the evolutionary capacity of the DPWeb without significant additional cost required by more traditional architectures, an important revision of the underlying data structure of the database.

In messaging, XML allows passing from the present fixed-order style to a more creative style based on a predefined model and tags embedded in the message. XML is able to represent structure within the documents. In this way, documents are made more independent from the applications used to generate them. Different
applications can work safely on the same structured document.

**Communication of multimedia data** is a crucial part of the integrated system. Synchronous teleconsultation includes a videoconferencing system or an application sharing system as TELES's "WYSIWIS" and "VISION-Starter," respectively. Asynchronous teleconsultation is achieved using multimedia e-mail.

In the RETRANSPALTNT project the end users use remote consultation systems: the Teleradiology System (TRS) and Telepathology System (TPS) from SAMBA Technologies, France. SAMBA's TRS & TPS are dedicated to telemedicine networks, allowing multimedia exchanges between distant healthcare organizations through common phone lines, ISDN links or LANs. SAMBA telemedicine systems enable the creation and mailing of multimedia documents in the area of Radiology and Pathology. SAMBA provides multifunctioning tools that can interface with its main products with information systems coming from other vendors. These accompanying products act as gateways attached to the main products and implement the appropriate standard interface protocols. SAMBA DICOM is an optional module that permits SAMBA telemedicine systems to receive images through the DICOM communication protocol.

**Integration of Electronic Medical Systems**

Working in the RETRANSPALTNT project, information and telecommunication systems must primarily provide the infrastructure allowing the effective integration of distributed and heterogeneous components;

- Smart Card -- EHCR
- EHCR -- Medical Imaging System
- Medical Imaging System -- Telemedicine
- Telemedicine -- Videoconferencing System
- EHCR -- EHCR
- EHCR -- Recipient Donor Selection

**RESULTS**

The RETRANSPALTNT project interfaces and integrates information technologies to support the development of Regional Organ Transplant Information Networks (ROTIN) in Hungary and Slovenia. The Transplant Information Portal (TIP) provides access to TPWeb from the Dialysis Centers and Donor Hospitals. The selection and matching system software, SELECT 4 (National Institute of Hematology and Immunology, Budapest, Hungary), does the immunological matching of patients. It is an electronic transplantation database which consist of several modules: the transplantation waiting list, the transplanted recipient archive, the donor-recipient matching tool, the matching procedure reports tool, and the survival analysis program. SELECT 4.0 is a new concept in information management for Kidney Transplantation. Based on a program running at the National Institute of Hematology and Immunology, Budapest, Hungary, the current version provides ultimate flexibility to serve the needs of other HLA laboratories and transplantation centers as well.

After the selection of the patient, the XML web patient records from Dialysis Centers, Donor Hospitals, and Tissue Typing Laboratories, are transferred to the Organ Transplant Centers' CrossWay HIS.

The main screen of DPWEB provides rapid visualization of the state of the file with reminders, the current problems, the actions to take or to do, and the results of the preceding consultations. The patient's medical history and allergies are permanently visible.

Two tabs enable a change of screen to: medication, prescriptions, or investigations. The definition of this screen corresponds to the wishes of the group in terms of being able to visualize immediately important information on their patients, without having to manipulate several screens. The clinical and therapeutic management system is particularly adapted to the demands/needs of practitioners who want a minimum number of screens for data capture, a simple decision support system and a permanent summary of the essential elements of the patient record. In the RETRANSPALTNT project the DPWeb application was adopted to transplant medicine and called TransPlant Web (TPWeb). The product includes an XML requester with vertical applications enabling the proposition of relevant information and services to the end users at Tissue Typing Laboratories, Dialysis Centers, Donor Hospitals and Transplant Centers. The product integrates and interfaces transplant patient web records (TPWeb) to EHR, HIS, donor-recipient matching system, medical multimedia records and smart card based security programs as well as maintaining consistency with EDI.

Medical Images (radiology and pathology) support the clinical decision making process using SAMBA DICOM images accessible from multimedia workstations at the participating health care facilities together with the electronic patient record. The SAMBA system consists of a Patient Data Base (PDB), a tool for storing information about patients, cases and examinations along with multimedia records. Each multimedia record is a collection of images, texts and voice records. Image Data Base (IDB) is a tool for storing images and accompanying data as a collection of reference images. No patient information is stored to allow the use of the database for training and tutoring.

Both the patients at the Dialysis Centers which are on the waiting list for organ transplant and the transplanted patients at the transplant centers carry smart cards. The Dialysis or Transplant Card with the physician's professional card provides access to respective electronic patient records; TPWeb, CrossWay HIS, SELECT 4 waiting list data and SAMBA multimedia medical images. Using the physician's personal identification card (PIC) and patient's smart cards ensures secure data sharing in the Regional Organ Transplant Organization.

**DISCUSSION**

A substantial proportion of future expansion of transplant medicine depends greatly on improved collaboration between the regional and international
transplant organizations, and effective sharing of data and expertise by different healthcare professionals. Creation and dissemination of clinical guidelines is finding increasing favour with clinicians and governments as a way to help clinical professionals keep pace with the avalanche of new clinical knowledge.

Use of IT in everyday transplant medicine has been shown to result in significant improvements in the organ transplant process and outcomes.

The RETRANSPALNT project has aimed to build on existing conventional clinical informatics systems by providing clinicians with network and multimedia health record-based decision support in transplantology. The diversity of hospital organizations, the complexity of clinical protocols and procedures, as well as the different preferences of various user groups made it extremely difficult to design a single monolithic information system to effectively serve the needs of an entire organ transplant organizational structure. As a consequence, users, e.g., transplant centers, dialysis centers, tissue-typing laboratories, selected the applications most suitable for their needs and requirements. In addition, a number of applications are already available for them. Therefore, the designed and implemented information and telecommunications systems primarily provide the infrastructure permitting effective integration of distributed and heterogeneous components.

CONCLUSION
Highly effective treatment for patients with end-stage diseases has resulted in a rapid increase in the number of candidates for organ transplantation. The direct, indirect, economic, and social costs associated with chronic and end stage diseases must all be considered when making a cost of illness estimate. While the need for transplantation is considerable, there are both clinical and economic factors limiting the overall level of activity. The RETRANSPALNT project has succeeded in its most difficult phase to integrate the Transplant Information Portal. As a consequence, the impact of RETRANSPALNT on the efficiency of the search for unrelated donors, and use of on-line multimedia consultation will directly lead to economic benefits for the health care systems involved.

The RETRANSPALNT project is sharing developed Transplant Information Portal tools, providing support for establishment of networks in European countries and regions, and educating transplantation medicine end users in the use of information technology.

Citizens, as patients, will benefit from a substantial improvement in healthcare, improvement in diagnosis through on-line access to European specialists, and on-line services from: practitioners at dialysis centers, tissue typing laboratories, donor hospitals and transplant centers.

Tax payers and public administrations will benefit from tighter cost control and cost savings in healthcare spending and an acceleration of reimbursement procedures.

Policy makers (politicians, authorities and governments) will learn the results of RETRANSPALNT projects to convince them of the effectiveness/efficiency of medical informatics.

REFERENCES

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