A National Organ Donation/Transplantation Registry System

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Abstract

This paper describes the system architecture, functionalities, and development of a National Organ Donation/Transplantation Registry System (NODTRS). First, an overall description on the use of information technology in NODTRS is presented, with emphasis on the national initiatives by the Department of Health, Taiwan. Then, HL7/XML Organ Transplantation Standard draft is proposed and its implementation in NODTRS shown. The adopted security and dependability methodologies are also discussed.

Keywords: dependability; HL7; organ donation; organ transplantation; registry

Introduction

Government in Taiwan had already announced a revised version of the Human Organ Transplantation Law (HOTL) at July 10th, 2002. This version relaxes the living donor limitation from three-level-relative to five-level-relative. Meanwhile, it creates another very important law for enforcing organ transplantation registry [1]. The Department of Health, Taiwan (DOH-Taiwan) was accredited to activate the Taiwan Organ Registry and Sharing Center (TORSC). Currently, TORSC is in charge of managing and monitoring the daily activities of organ donation and transplantation. Her final goal is to increase the quantity of the organ donation and let all of the donated organs be reasonably, fairly, and effectively distributed to the most appropriate recipient [2].

There are some facts that we should note here. For example, the Tzu-Chi Foundation created her bone marrow transplantation registry system in Taiwan at Oct. 1993 and within two years, there have been 100,000 bone marrow donors. Now she becomes the third largest bone marrow registry in the world and the largest in Asia [3].

On the other hand, since the National Taiwan University Hospital (NTUH) owns a highly respectable reputation of organ transplantation in Taiwan medical field [4], honorably, NTUH was accredited by DOH-Taiwan and demanded to set up a National Organ Donation Transplantation Registry System (NODTRS) from Jan. 1st to June 30th, 2003 [1]. Records listed in **Table 1** could explain why NTUH be accredited by DOH-Taiwan.

Table 1. Records of first organ transplantation in NTUH and Taiwan

Organ	Donor Status	Operation Time	Hospitals
Kidney	Living	May 27, 1968	NTUH
	Cadaver	May, 1969	NTUH
Liver	Living	Mar. 23, 1984	CGMH
		Oct. 13, 1989	NTUH
	Cadaver	June 17, 1994	CGMH
		Dec. 27, 1997	NTUH
Heart	Living	July 6, 1987	NTUH
Lung	Living	July 10, 1991	VGH
		Dec. 9, 1995	NTUH
Pancreas	Living	Nov. 24, 1994	NTUH

Fortunately, NTUH achieved this project on schedule and succeeded to propose a draft of the HL7/XML Organ Transplantation Standard. NODTRS was announced nation wide and used to educate transplantation surgeons on Aug. 2nd, 2003 [1][2].

Since the HIS environments among different hospitals are highly heterogeneous in Taiwan, we choose the J2EE solution with component reuse concepts to solve this problem and let every hospital can easily connect to TORSC with no pains [5][6][7].

NODTRS

The goals of NODTRS are listed as follows. (1) To construct organ transplantation data from pre-operation registry, pre-operation auditing, post-operation registry, donor registry, pre-/post-operation query, and matching mechanism. (2) To merge the pre-operation auditing application form from the National Health Insurance, Taiwan (NHI-Taiwan) and the registry form from TORSC into one new form in order to decrease document flow time. (3) To use the integrated data in NODTRS to accurately and speedily achieve the matching mechanism. (4) To construct a reasonable organ transplantation waiting list within the non-stopped NODTRS. (5) To constitute the HL7/XML Organ Transplantation Standards, and (6) To guarantee reliability for the software reuse components in NODTRS.

From the six goals of NODTRS, we implemented six sub-systems to process related activities. The six sub-systems are (1) Organ Waiting Registry System (OWORS), (2) Pre-operation Auditing System (PreOAS),

(3) Donor Registry System (DRS), (4) Post-operation Registry System (PostORS), (5) Matching Rule System (MRS), and (6) TORSC Management System (TORSCMS), as illustrated in **Figure 1**.

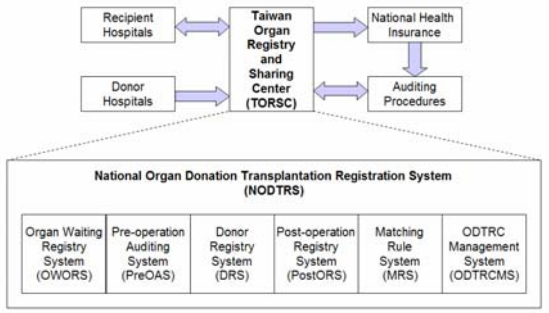

Figure 1. System Modules in NODTRS

OWORS

OWORS is used to include the pre-transplant registry data of the patients in the waiting list. Currently, the data included in OWORS are heart, liver, lung, and kidney. The total patient waiting list is estimated to be 10,000 and the TORSC plans to extend the service to transplantation of pancreas, bone, bone marrow, cornea, etc in the near future.

PreOAS

PreOAS is used to audit the waiting lists of heart, liver, and lung and check whether a patient could be accepted an organ transplantation recipient. It is not required now to do the pre-operation auditing procedure of the kidney transplantation in Taiwan.

If the pre-operation registry data does not follow the procedures which are defined by NHI-Taiwan, then NHI-Taiwan will not pay the related medical fee of this organ transplantation operation. Generally, the status of recipients in a waiting list could be divided into six statuses: (1) under auditing, (2) pass auditing, (3) non-pass, (4) transplanted, (5) death, and (6) cancelled.

DRS

Donor data including demography etiology of brain death, pre-donation condition, etc are recorded.

PostORS

After a recipient accepted the organ transplantation operations, we could copy the related data from the OWORS database to the recipient database and append the operation notes, post-operation reports, discharge notes, observation reports, and laboratory reports of that recipient. Of course, the donor and recipient database will be linked together for further reference.

PostORS is used to serve about 200 patients per year and trace their post-operation statuses. This system could be integrated with the hospital information system (HIS) of a hospital forming a highly-coupled information exchange environment to support organ transplantation surgeries with more related clinical reports and to promote the qualities of the post-operation services.

MRS

After a hospital inputs the donor data, NODTRS can automatically execute the organ matching rules to create a real-time matching list for each donor organ. This organ matching-list could be sorted by a specific key and be listed under the donor lists. If an organ cannot be accepted for an organ recipient with higher priority, the recipient doctor should comment the case with some reasons.

TORSCMS

TORSCMS is a central management system for TORSC usage and automatically create statistics reports for DOH-Taiwan reference.

System Architecture of NODTRS

NODTRS is a 3-tier J2EE application that uses a browser to access the application server components. Typical J2EE program components used in NODTRS include JavaServer Page (JSP), Servlet, Java Beans, and Enterprise Java Bean (EJB). **Figure 2** describes these application modules.

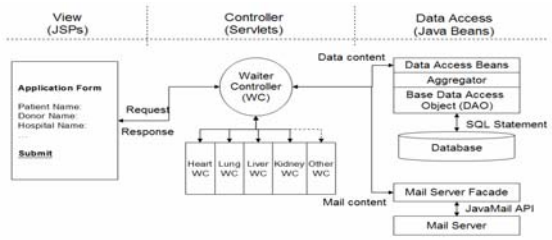

Figure 2. Application Modules in NODTRS

NODTRS uses Microsoft SQL Server 2000 as a database server and WebSphere 4.04 as an application server in order to support the Type 4 JDBC Driver for the Microsoft SQL Server 2000.

HL7/XML Organ Transplantation Standard

Before we look inside this standard, we will briefly describe our experience in the implementation of HL7/XML standards in Taiwan [8]. First of all, **Figure 3** illustrates that some software reusing components have been built based on the these standards. Obviously, each of the communicating system sides should implement an HL7/XML interface. If no one could propose a better way to communicate two more heterogeneous systems among different healthcare organizations, it is quite necessary and no doubt for us to spend more cost and time to implement these two HL7/XML interfaces for connecting two different systems.

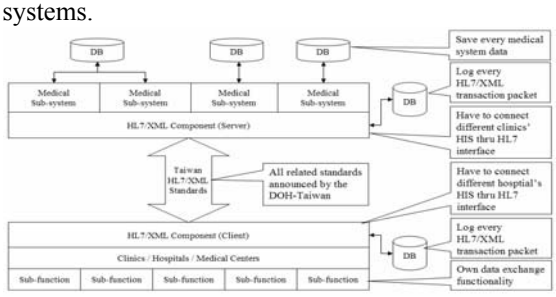

Figure 3. Software reusing components based on the HL7/XML standards

Figure 4 illustrates the software reusing components based on three different HL7 standard drafts in Taiwan now. These three different HL7 standard drafts are HL7/XML Referral standard (white paper draft) v1.103c, HL7/XML Disease Surveillance standard draft v0.4, and HL7/XML Organ Transplantation standard draft v0.5.

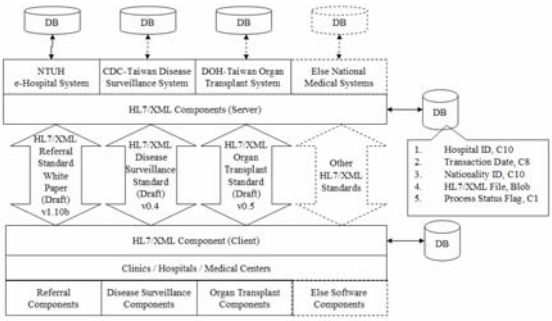

Figure 4. Software reusing components based on the HL7/XML standard drafts

Inside this standard draft, we created a new HL7 message ZOT with trigger event Z01 to carry the donor and recipient data. This ZOT message is referred from HL7 REF^I12 and ORU^R01 messages and uses REF as main reference. Note that the REF^I12 is mainly used to carry patient and provider information between the hospital referral processing. On the other side, the ORU^R01 presents an updating laboratory or observation data to the corresponding application trigger event. **Table 2** illustrates the ZOT^Z01 message structure.

Table 2. HL7 ZOT^Z01 message structure

ZOT^ZO1	Organ Transplantation	Ref.
MSH	Message Header	REF, ORU
[RF1]	Transplantation / Donation Information	REF
[AUT	NHI-Taiwan Auditing Information	REF
[CTD]	Contact Data	REF
]		
{PRD	Transplantation / Donation Hospital Information	REF
[{CTD}]	Contact Data	REF
}		
PID	Patient Identification	REF, ORU
[{NK1}]	Relatives Information of Donor	REF, ORU
[{GT1}]	Guarantor	REF
[{IN1}]	Insurance Information	REF
[{DG1}]	Diagnosis	REF
[{DRG}]	Diagnosis Related Group	REF
[{AL1}]	Allergy Information	REF
[{PR1}]	Procedure / Operation Information	REF
[{OBR	Observation Requests	REF, ORU
[{NTE}]	Notes and Comments	REF, ORU
[{OBX	Observation Results	REF, ORU
[{NTE}]	Notes and Comments	REF, ORU
}		
]		
}		
]		

From the above Table 2, we could see that we do not use the OBR^R01 segment yet. That is, we reserve it for further usages. Since each of the registry forms in NODTRS contains more than 200 items and many of the data could not be offered yet by any of the registry hospitals, we constitute this standard draft v0.5 by covering some commonly-used data for the heart, liver, kidney, and lung. These commonly-used data include provider information, recipient and donor basic information, diagnosis, disease history, laboratory reports, and observation reports, etc. We implement an HL7 Interface Engine (HL7-IE) to route the ZOT^Z01 messages and this HL7-IE is Orion Rhapsody v1.3 [9][10][11].

Security Management

NODTRS offers specific IP segments to let specific organ transplantation contracted hospital (OTCH) to input the patient data in the recipient waiting list. For example, NTUH should first apply an account for her organ transplantation group users and then TORSC will assign specific IP segment to them. However, the donor data is free of IP segments limitation.

The user of a specific organ could login a specific organ system only. That is, the heart surgeon of an OTCH could login NODTRS and browse the heart transplantation, donation, and registry data only. Meanwhile, each OTCH should provide at least one specific e-mail address to communicate some urgent information with NODTRS and TORSC. The e-mail message will be encrypted with an Healthcare Certificate Authorization (HCA) mechanism after the HCA integration becomes available [1].

System Dependability

In order to enhance NODTRS dependability, we have to add more software and hardware components to achieve this goal [12][13][14]. **Figure 5** illustrates the data replication and global network / database fail-over mechanism for NODTRS.

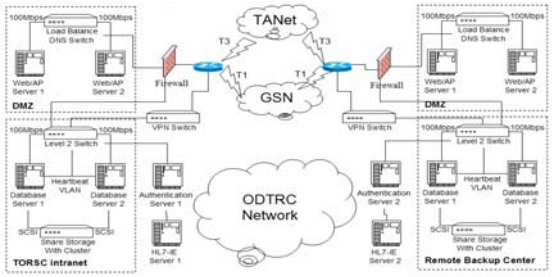

Figure 5. Data replication and network / database fail-over mechanism for NODTRS

Unfortunately, due to short of project budget, NODTRS has only implemented part of **Figure 5**. Anyhow, we propose this full system architecture for the next generation of NODTRS.

Note that the demilitarized zone (DMZ) will act as a neutral zone between organization's private network and outside public network. Generally, the DMZ solution is optional and is an approach more secure than a firewall, thus it can effectively act as a proxy server as well. Inside the NODTRS DMZ area, we guarantee the web server and application server will load balance each other. On the other hand, the TORSC intranet and the remote backup center areas will process database systems with the on-line

fail over database cluster mode.

Conclusions

The active organ transplantation medicine in Taiwan motivates us to build this NODTRS to integrate all of the organ donation and transplantation registry data. We hope this NODTRS could be another new milestone for organ transplantation not only for the one living in Taiwan, but also for the Asia Pacific people soon, and eventually for the whole world. Another view-point is that the matching rules of MRS in NODTRS are the domain know-how for all of the famous surgeons in NTUH. Without their kindly donations of their domain know-how, this system will decrease her accurate utilities or become nothing sooner or later.

Many future implementations could be taken to refine NODTRS. (1) To integrate the HCA-Taiwan mechanism which was announced nation wide at June 13th, 2003 and to guarantee the authentication. (2) To implement the national tissue bank system and process the donor screening, tissue storage, and tissue distribution activities. (3) To easily modify the related matching rules in MRS to promote the further live ratio of post-operation. (4) To integrate with heterogeneous HIS data among different hospitals with HL7/XML standards to a tightly-coupled data exchange and sharing environment in order to increase the PreOAS and PostORS reference data, even real-time accesses. And (5) NODTRS should implement dependable mechanism to guarantee the everyday usages.

Acknowledgements

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