

National Transplant Network Information System of US and England

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Abstract

Introduction and Objectives: National Transplant Network leads to integration of transplant activities chain amongst participating centers. Co-ordinate and timely information exchange among those centers is a key requirement of integration which is made possible by information system. The present research studied US and England National Transplant Network Information System.

Background: In National Transplant Network of US, United Network for Organ Sharing, American Association of Tissue Banks, and National Marrow Donor Program have safe and online information systems which deal with the management of data associated with organs, tissues, and cells transplants respectively. The American Division of Transplantation in the department of Health and Human Services supervises the activities of these systems. In England, also the management of transplantation data is supervised by Department of Health and through information system of National Health Services, Blood and Transplant organization, where in addition to variety types of transplantations it comprises the data associated with blood supply chain.

Findings: National Transplant Network Information System in US and England has such important characteristics as integrated management of the entire data related to transplantation types, clarity of data set, and the nature of their exchanges as well as precise and on time flow of information amongst network components which are supported by infrastructure features including government legal and financial backing, supervision of Health Ministries and involvement of policy making organization on national level.

Conclusion: Given the breadth of transplantation services in US and England, via a precise and on time information flow, National Transplant Network Information System has created coordination amongst the components of National Transplant Network and consequently provided a comprehensive and equitable service nationwide.

Keywords: National transplant network; National transplant network information system; Transplant data management; Coordinated flow of transplantation information

Introduction

Nowadays, as the number of cases suffering from end stage diseases is on the rise, there is an upward trend in the rate of transplantations [1,2]. This approach, considered a fruitful and cost-effective therapeutic measure [3], has significantly reduced the mortality rate of patients whilst simultaneously improving their quality of life and cutting down the treatment costs [4,5].

There are different types of transplants (organs, tissues, and cells) [6]. Using them to treat diseases necessitates cooperation between different organizations and institutes like organ procurement organizations, histocompatibility laboratories, tissue banks, cord blood banks and transplant centers. These organizations are responsible for a host of specialized activities regarding the management of transplant donors and recipients. Efficacy of these activities and achieving positive outcomes demands their coordination and coherence which is made possible through a National Transplant Network (NTN) [7-9].

As two successful cases, the NTN in the US and England have devised a goal-oriented structure for management of the chain of

transplant activities. In these networks, all organizations and centers have been organized nationally with specific roles, cooperation and clear available information. This would in turn lead to coordination of transplant activities such as donor identification, procurement and processing, allocation and distribution of transplantable organs while managing the national waiting list and existing recipients. Among the most significant outcomes of NTN, increment in transplant rates and fair nationwide distribution of transplantable organs can be mentioned [10-13].

Coordination amongst the components of NTN is achieved by the information systems of those networks where provide the possibilities of information exchange. National Transplant Network Information System (NTNIS) is a system for the collection and processing of the data as well as information distribution on transplantation which include data such as patients on waiting lists, living and deceased donors, matching, and generally data related to the donors and recipients of transplantations before, within, and after procedure [14-16]. These systems are employed by the whole participant centers for the management of data and creation of information flow. Given the positive outcomes that these systems have created in NTN of US and England, the present study has attempted to investigate the features of NTNIS to be instructive for the countries like this system.

Literature Survey

Management of transplant services in the US

Early transplantations in the US date back to 1870. Numerous tissue transplants including cornea, skin, joints and blood vessels were completed successfully in that decade and in the following years. As these transplants developed further, there was the need to establish centers to manage tissue processing and procurement. This led to the establishment of the first tissue bank in 1949 which was capable of recovering, processing, storing and distributing different tissues scientifically [17]. With the ever-growing number of such banks, American Association of Tissue Banks (AATB) was founded to provide uniform services in transplant centers by making them coordinated and coherent [18]. Moreover, the AATB devised comprehensive and clear standards and regulations to improve the quality and immunity of donated tissues and provide fair and comfortable access to them to cater for domestic needs [19,20].

Concomitantly, as the tissue transplant expanded, the bed was being made for organ transplants as well. It was in 1968 that the first Organ Procurement Organization was established. Also, the Southeast Organ Procurement Foundation was formed with the aim of quick and fair distribution of donated organs. This foundation developed the first computerized system able of finding appropriate transplant candidates through donor-recipient compatibility and in order to provide these services nationwide, it was renamed in 1984 to United Network for Organ Sharing (UNOS). Meanwhile, the National Organ Transplant Act was passed in the congress thereby prohibiting the sales of human organs. Also, the government was obliged to establish an Organ Procurement and Transplant Network (OPTN) which emphasized on establishing, developing and specializing cooperating organizations and centers in this regard. In 1986, the US Department of Health and Human Services was, based on this legal obligation, charged with signing the contract with the privately owned UNOS to implement OPTN. The purpose of establishing this network was fair allocation and distribution of donated organs through coordination of participating centers [21,22].

There were also other efforts towards hematopoietic stem cell transplant. These were conducted by National Marrow Donor Program (NMDP) supervised by the HHS [23]. The main purpose of this organization was to make possible cell transplants from volunteer unrelated donors; being there no compatible donors among the relatives of approximately 70% of the patients. In order to achieve this objective, "Be the Match" was created by the national registry in which now reside the contact details of 11 million volunteer donors and 193000 cord blood units as well. Furthermore, the NMDP manages collecting and processing of stem cells, the transplant procedure, follow up of donors and recipients after the transplant and ensures their safety [24].

According to the aforementioned facts, it is clear that the transplant process in the US is a result of the need for any type of transplant (organs, tissues, and cells) through time. Currently, these activities are managed by a network of three mentioned organizations i.e., UNOS, AATB and NMDP [25-27]. These organizations which shape the American NTN are supervised by the Division of Transplantation (DoT) in the HHS [10]. This entity would devise general policies to guide the network and supervise the implementation of such policies by the abovementioned organizations [28,29].

Each of these organizations encompasses a series of coherent centers in order to accomplish their tasks. Accordingly, the UNOS includes organ procurement organizations, histocompatibility laboratories, and organ transplant centers. The AATB also oversees the tissue banks and tissue transplant centers. The components of the organization responsible for executing NMDP are recruitment centers, donation centers, stem cell collection centers, apheresis centers, cord blood banks, histocompatibility laboratories and stem cell transplant centers. All these centers are of clear duties and interrelations under their overseeing organization. The existence of organized communication between these centers has led to further coordination in the chain of activities from identification of donors to the transplant follow ups [30-32].

The above mentioned organizations have their own structured entities to devise executive policies and operational procedures regarding transplant. These policies are put forward by specialized committees and are to be assessed and approved by the HHS for nationwide execution [24,28,30-32]. One of the most important policies relates to how transplantable parts are allocated to the existing patients on the waiting list. They are devised according to scientific principles and criteria and can result in fair distribution of transplant products throughout the country [33].

The American NTN enjoys strong computerized infrastructures used to exchange information between transplant centers. This data exchange is done using an internet-based system, coherently and securely connecting the components of NTN. All the data regarding living and deceased donors, patients on the waiting list, compatibility, matching and transplant procedures are saved in a national database [34,35].

Management of transplant activities in the England

The first transplant procedure, a cornea transplant, was successfully done in England back in 1905. A kidney transplant was first performed in 1960. The National Tissue Typing and Reference Laboratory was established in Bristol in 1968 in order to determine the compatibility of donors and recipients. Subsequently the first National Organ Matching and Distribution Service was formed in 1972. Having access to detailed information on the donors and transplant candidates, this service was looking for fair distribution of transplantable parts. In 1979, they merged and formed the England Transplant Service which was later renamed to The England Transplant that further merged with the National Blood Service in 2005 to cut down on costs and localize interrelated activities. Hence, the National Health Services, Blood and Transplant (NHSBT) was established which currently manages transplants in the England [36]. Following the establishment of this organization, the Human Tissue Act was ratified leading to the establishment of the Human Tissue Authority. This entity was responsible for compiling regulations regarding recovering transplantable parts, processing, storing, distributing and using them [37,38].

According to the aforementioned facts, the development process of transplant activities and the related organizations is indicative of England's desire to confer coordination and coherence between transplant services. Consequently, a network of related organizations and centers has been created operating under NHSBT [13,39]. Responsible for policy making, supervision and execution of the network activities, this network has three main parts, namely Organ Donation and Transplantation, Diagnostic and Therapeutic Services and Blood Supply [40-42]. Operating in coordination, these centers

manage activities related to organ, tissue and stem cell transplants, and also blood and blood products supply [40]. The Organ Donation and Transplant manages organ transplant procedures in order to cater for the needs of patients on the waiting list [41,43]. The Diagnostic and Therapeutic Services manages specialized centers including tissue services, stem cell services, histocompatibility laboratories, red cell immunohematology and apheresis treatment center [41,42]. The blood supply service is the only blood products procurer and manages all the activities related to collection, processing and distribution of blood to the hospitals as part of the blood supply chain [44,45].

All the above mentioned organizations and their affiliated centers are interrelated and are managed by the NHSBT Duty Office. The ODT encompasses referring hospitals, Organ Donation Services Team, National Organ Retrieval Services and organ transplant centers. Also, the Tissue Services has at its disposal numerous hospitals or donor referring centers, National Referral Center, tissue bank and tissue transplant centers. Registration, collection and processing centers of stem cells as well as cord blood bank and stem cell transplant centers, come together and shape the Stem Cell Services. Furthermore, blood supply center includes blood collection, processing and distribution centers and hospital blood banks [46].

Operating procedures and strategies as well as executive policies of these organizations are devised by the specialized groups and committees in NHSBT. This means that the policies are made scientifically and comprehensively. One such unit is the transplant policy revision committee. This committee defines and revises up-to-date policies and criteria regarding transplant products allocation [40].

NHSBT considers cutting-edge computerized infrastructures essential to the management of transplant and blood data. Accordingly, the eTransplant computer system is utilized to manage transplant data and PULSE handles blood data. Having rich databases, these systems have made it possible for an information flow to be created between cooperating organizations in the network, hence coordinating their efforts [47-49].

Results and Discussion

The NTN in the US and England enjoy of strong computerized infrastructures to support the data management [34,35,47-49] which have led to prominent features for them. Countries lacking such systems can draw on the experiences and achievements of these two networks in forming their own NTNIS. These features are given in Table 1.

Country/ Features	The US	England
Integrated management of entire data related to all types of transplants	Organs, tissues, and cells data [15,50,51]	Organs, tissues, cells, and blood data [47-49,52,53]
Clarity of data set of network components, and the way they are exchanged	Data set of UNet (organs), AATB (tissues), and NMDP (cells) [50-52]	Data set of eTransplant [Organ Donation and Transplant (organs), Tissue Services (tissues) and Stem cell Services (cells)], and PULSE (blood) [54,55]
Precise and on-time information flow amongst the network components	Clarity of data exchange between participating organizations and centers [26,50,51]	Clarity of data exchange between network components [55,56]

Supervising NTNIS by the health departments	Complete supervision of network and NTNIS by the DoT [10,28]	Supervision of network and NTNIS by the NHSBT [13,53]
Existence of coherent establishments to make policies about data management according to scientific evidences and principles on a national level	Establishing specialized committees and making policies in cooperation with them according to scientific principles while considering the needs in different parts of the country with up-to-date policies [28,31,32]	Establishing specialized committees including representatives from different sectors in order to devise operational strategies and procedures while adopting up-to-date transplant policies [40]
Legal and financial support of government	Legal and financial support of network and transplant data management [21,22]	Legal and financial support of all transplant activities and data management [37,38]

Table 1: Prominent features of national transplant network information system in the US and England.

Paying attention to the features of the American and English NTNISs demonstrate that these systems have two groups of characteristics. Some are core or main features related to the professional aspects including the integrated management of entire data related to all types of transplants, clarity of data set of network components and the way they are exchanged, and precise and on-time information flow amongst the network components. The second group, which play a supporting role for the core ones are in fact infrastructures including supervision by health departments, coherent policy-making establishments as well as government support and commitment.

Investigating main features of the NTNISs in the US and the England is indicative of the fact that they comprehensively cover their transplant data. In other words, these systems are able to manage all transplant data including organs, tissues, and cells. This feature is one of the most prominent in the NTNISs because there is a wide spectrum of transplant patients [49] requiring a certain type of transplant that the comprehensive inclusion of data to all these transplants play a crucial role in improving the results of their treatments. It is also employed in policy making associated with all types of transplants as well as research implementations [57].

NTNIS in the US and England comprises a defined data set which have been determined based on information requirements of the network components. Developing standard data set with defined terminology is one of the data exchange requirements which has been studied by Ciaccio et al. where attempted to standardize data set for creating of information flow amongst participating centers at the level of European countries [58].

Offering extensive transplant services to all candidates demands network coordination and coherence. This feature of both networks in the US and the England is clearly observable through the exchange of information between the cooperating entities. These features gain more importance when taking into account the limited number of donors and the essentiality of using that limited capability to meet demands [59,60]. Moreover, considering the value of time in the process of transplant, there is the necessity for a connection to be made between the donors and the recipients' data. This entails coordination between donor identification centers and procurement centers on one hand and the histocompatibility laboratories and transplant centers on the other, to enable fast selection of suitable candidates and perform the transplant [61].

Another set of features of the NTNISs in the US and the England is the infrastructural features. By analyzing them, it is seen that the health departments of both countries completely oversee the transplant services and data management. This supervision means that organizations and centers produce and exchange their data correctly and in coordination with others and in doing so, it is made possible for the recipients to be identified in time and for the candidates to be organized while matching are performed between donors and recipients [60].

One other key feature of the NTNIS in the US and the England is structured policy making organizations for them. This particularly gains significance since these policies provide practical guidelines and if adopted scientifically and according to the needs of different groups, the transplants are performed based on scientific evidence. Moreover, nationwide shared policies will result in coordination in the network [61].

Development, stability and continuity of NTNIS activity also demands support by legislators and governments [25,61]. In fact, support by and commitment of these entities, in form of enforcing required legislation and enabling their execution, mean that management of transplant services and their data in the network will be considered national priorities enjoying legal and executive guarantees for stable operation.

Given the necessity of NTNIS for achieving the positive outcomes, countries lacking this system should take steps to develop it. The most important of these steps, enculturation in the field of transplant information systems integration at top level decision makers. Next steps are legislation and making legal requirements, as well as establishing a specialized center in the ministry of health for managing NTNIS. This Center should be responsible for supplying hardware and software infrastructures, standard dataset, electronic data exchange guidelines, and supervising information network permanently.

Conclusion

NTN in the US and England has a strong and safe computerized network for accurate and on-time transplant data management. These systems due to the breadth of transplant services and plurality of participating centers have created coordination through making essential data accessible at a required time. This resulted in providing integrated transplant services nationwide. Also, integrated registration of donors' data has paved the way for the optimal use of existing potential in terms of donation in one hand, and recording the patients' information on national waiting list, also quick and precise matching of these data on the other hand has facilitated on-time positioning of donated organs as well as escalating the number of transplants. Equitable allocation and distribution of donated transplantable parts are the other advantages of these systems which allocate them based on defined computer algorithms. Being aware of these features can be instructive for countries lacking NTNIS in implementing this system and improving the quantity and quality of transplant services at nationwide.

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