EMDIS

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European Marrow Donor Information System

From 1992-01-01 to 1994-12-31

Project details

Total cost: Not available
EU contribution: Not available
Coordinated in: France

Objective

1) To decrease the waiting time for the EC registered patients also augmenting their expectancies of life, independently of their origin countries, by means of networking Distributed Data Bases 2) To define EC standards and adopt common ethical rules and procedures to the access to the Network, also to avoid illegal traffic in transplants.

The allogenic Bone Marrow Transplantation (BMT) using a volunteer donor has already become an acceptable alternative treatment for a patient who has no HLA identical family donor and who is suffering from hematologic malignancies such as marrow failure disorders, immunodeficiency syndromes and certain metabolic diseases. Several reports have already given results in large series and concluded that this marrow procedure has been of benefit for a significant number of patients.

Due to the very large polymorphism of the HLA system and the necessity of finding a phenotypically HLA-identical donor, the chance for a registered patient of finding a suitable donor is on average one in a million. Consequently, it is impossible for any country, alone, to develop a registry of sufficient size. Only cooperation at the European level could improve the probability of finding a suitable donor.

Beyond the practical and functional level, safety, security and confidentiality of all data in the system are of critical importance in EMDIS. This concern is emphasised by close contacts to security related AIM projects and to competent national organisations. The telematic procedures will guarantee the above properties much more perfectly than current manual handling.

The realisation of EMDIS consequently uses methods of modular design and will adhere to standards for data encryption and transmission.

The success of a bone marrow transplantation critically depends on the early availability of a suitable donor. In order to streamline the process of European search for matching bone marrow donors, this project will build up an efficient, fully automated communication system between twelve bone marrow donor registries in Europe that currently function as national coordination centres (hubs). The system will have a decentralised and cooperative structure with all hubs in it having equal functionality. It will cover the information structures from the preliminary search through all refining steps in the identification of a suitable donor to the preparation of the transplantation.

Technical Approach

EMDIS is going to set up a network composed of gateways running SCO UNIX of appropriate performance and size functioning either as national computer system in countries which do not yet have a satisfactory computer system of their own or as a front-end to existing national structures if necessary. EMDIS uses a portable SQL-based relational database Informix and with a suitable 4GL for the implementation of most applications. International communication will be based on the exchange of
encrypted plane ASCII text files through TCP/IP over X.25 lines and, as soon as available for participants, ISDN. At this moment (December 1992), a mini pilot between the three partners (France, Germany and the United Kingdom) is running using two approaches in telecommunication system: the electronic mail and the client/server architecture. A critical review of these two approaches will permit a choice between the two alternative ways or any other additional way.

So, EMDIS will rely on modern technology of “Open Systems” and show that with cost-effective standard components a reliable, flexible and powerful wide area communication system can be built.

Key Issues

The first phase of EMDIS gave a complete software requirement specification for the hub tasks (national coordination centre). The international communication will be based on a detailed consensus of all participating institutions.

After the implementation, the software will be used by all participants for communication and, as far as deemed necessary, also for all local tasks. The software design will be modular top-down, completely hardware independent and easily extensible for new tasks.

The whole system must be user friendly and easy to learn, fast and reliable. Safety, security and confidentiality of all data are the major concern of the development team and all participants.

Relationship to Previous Work

Until now, registries in twelve countries exchange data by dial up modem lines. This pilot system was developed by the coordinating partner of the present project. It has resulted in a tremendously increased in flow of information. This proved the necessity of a thoroughly automated system covering all subfields of the complex bone marrow donor identification process with connections to even more partners.

Expected Impact

Searching in many registries with EMDIS will not result in any extra workload either for the searching or for any asked registry. Moreover, common communication structures to registries outside the community will reduce the workload from incoming search requests to all participants. The automation envisaged will speed up the donor search and decrease error rates. To propagate these achievements, new registries can be easily integrated.

BMT has become a very effective and attractive form of treatment. Therefore, EMDIS will directly result in a significant economic benefit for all participating countries and the Community by making this kind of treatment accessible for more patients with acute form of diseases. It will also permit for small registries to reach an European Size faster, having access to the "pool" of European donors without making any additional expenses.

Related information

| Report Summaries | EMDIS: European marrow donor information system |

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