Global observatory on donation and transplantation


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SUMMARY - The mission of the World Health Organisation (WHO) is to meet the requirements of the Fifty-seventh World Health Assembly Resolution WHA57.18. This Resolution requested the collection of global data on the practices, safety, quality, efficacy and epidemiology of transplantations, their global availability for all those concerned, including professionals, patients, politicians and the general public, which is recognized as a prerequisite for global improvement of and better access to transplantations. To achieve these objectives, the WHO developed the Global Knowledge base on Transplantation (GKT). GKT1 and GKT2 led to the Global Observatory on Donation and Transplantation which is being developed by the Spanish Transplantation Organisation in collaboration with WHO. The Global Observatory on Donation and Transplantation (GODT) will provide an interface for health authorities and the general public to access data on donation and transplantation practices and legal frameworks.

INTRODUCTION

Currently more than 90,000 patients per year worldwide receive a grafted solid organ and the demand is increasing continuously owing to greater experience and better results.

Although several countries, mainly in the developed world, have introduced compulsory registration of transplantation procedures, and some voluntary registries also exist, no comprehensive system exists to collect data on the different types of transplantation all over the world. The lack of documentation makes it difficult to estimate the extent of ethically unacceptable practices or the relative efficacy and safety of transplantation in the different conditions and settings.

WHO

The World Health Organization is the United Nations specialized agency for health. It was established on 7th April 1948. WHO’s objective, as set out in its Constitution, is the attainment by all peoples of the highest possible level of health. Health is defined in WHO’s Constitution as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

WHO is governed by 193 Member States through the World Health Assembly. The Health Assembly is composed of representatives from WHO’s Member States. The main tasks of the World Health Assembly are to approve the WHO programme and the budget for the following biennium and to decide major policy issues.

WHO AND TRANSPLANTATION

(www.who.int/transplantation)

Following Resolution WHA57.18. of the World Health Assembly in May 2004, transplantation became an area of work at WHO. The mission of WHO on transplantation

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is carried out by the Clinical Procedure unit in the Department of Essential Health Technologies (EHT/CPR). The Clinical Procedures unit is responsible for promoting the ethics of donation and transplantation and the appropriate effective and safe use of cells, tissues and organs for transplantation.

The mission of WHO in the area of transplantation is to meet the requirements of the Fifty-seventh World Health Assembly Resolution WHA57.18.

Objectives can be summarized as follows:
1. To work with Member States and to provide assistance at their request to ensure effective national oversight of allogeneic and xenogeneic transplantation activities. This would ensure accountability, traceability and appropriate surveillance of adverse events (in particular transmission of infectious agents of xenogeneic origin).
2. To increase the access of citizens to safe and effective transplantation of cells, tissues and organs. Additionally, to ensure ethical and technical practices from procurement of human material for transplantation to the follow up of recipients and live donors.
3. To promote international cooperation to encourage the global harmonization of technical and ethical practices in transplantation. This would include the prevention of exploitation of the disadvantaged through transplant tourism and the sale of human material for transplantation.
4. To encourage donation of human material for transplantation.

To achieve the objectives of Resolution WHA57.18, WHO has developed the Global Knowledge base on Transplantation, a tool that is being elaborated over time as information becomes available and networks are established. Its primary role is to provide access to comprehensive information on transplantation to all who are interested for lay or professional reasons.

The GKT has four components that are being developed:
- GKT1 activities and practices in allogeneic donation and transplantation: number of donations and transplantations carried out globally, access and outcomes of transplantations.
- GKT2 legal framework and organizational structures for allogeneic transplantation.
- GKT3 threats and responses, reference information and vigilance and surveillance of risks to safety and ethics in transplantation.
- GKT4 xenotransplantation.

GKT1 and GKT2 led to the Global Observatory on Donation and Transplantation.

ABOUT ONT (www.ont.es)

The Spanish National Transplant Organisation, Organización Nacional de Trasplantes (ONT), is the technical coordinating organism of the Spanish Ministry of Health and Consumer Affairs, in charge of developing functions related to the procurement and clinical use of organs, tissues and cells. ONT’s structure is based on a reticular organization at three different levels: national, regional and hospital coordination.

To accomplish its functions, ONT acts as a technical operative unit. According to the principles of cooperation, efficacy and solidarity, ONT coordinates and facilitates the activities of donation, extraction, preservation, distribution, exchange and transplantation of organs, tissues and cells across the Spanish health system.

ONT acts as a service agency for the national health system, promoting a continuous increase in the availability of organs, tissues and cells for transplantation. ONT guarantees their most appropriate and correct distribution according to technical knowledge and the ethical principles of equity that should govern transplantation activity.

The main objective of ONT is therefore to promote altruistic donation with the sole goal that every Spanish citizen who needs a transplant has the best possibility of obtaining one. Since the creation of ONT in 1989, Spain has progressively become the country with the highest rate of organ donation, not only in Europe but also in the world, thanks to the implementation of the internationally called Spanish Model, a group of organizational measures to improve organ donation. This model is widely described in literature. It has been recommended by WHO and is being applied throughout the world with similar results to those obtained in Spain.

The Spanish outcome with regard to organ donation has led ONT to be an international reference when facing the problem of scarcity of organ donors, with numerous requests for cooperation at the institutional and professional level across the world.

WHO-ONT Collaboration

In May 2004, Resolution WHA57.18 of the World Health Assembly concerning human organ and tissue transplantations was signed. This Resolution requested the collection of global data on the practices, safety, quality, efficacy and epidemiology of transplantations. Another request was their global availability for all those concerned, including professionals, patients, politicians and the general public, which is recognized as a prerequisite for global improvement of and better access to transplantations.

Due to the extensive experience of ONT in creating and maintaining a data base on transplantations, derived from European databases on behalf of the Council of Europe, and its ongoing extension to the countries of South Amer-
ica through the Alianza Programme, the cooperation between Spain and Latin America and the network of health authorities responsible for transplantations, set up by the Pan American Health Organization (PAHO/AMRO) and the collaboration that has existed in recent years between HTMP/EHT/CPR and ONT, it was proposed to include ONT as a WHO Collaborating Centre. The structure, background, stability and experience of ONT was then offered to WHO to support a partnership in developing an international Observatory of Transplantation that could cover some of the objectives drawn up in the WHO 57.18 Resolution.

As a Collaborating Centre, ONT will provide the necessary technical support and funding to develop and maintain such a programme. The main aims can be summarized as follows:

1. Development and maintenance of a Technical Unit covering the following activities: data collection, analysis and validation, production of reports, development and maintenance of the electronic information platform.

2. Development and maintenance of a Coordinating Unit covering the following activities: administrative link with WHO Headquarters, scientific and advisory board, organization of meetings, planning and implementation of new programmes.

GLOBAL OBSERVATORY ON DONATION AND TRANSPLANTATION (www.transplant-observatory.org)

The Global Observatory on Donation and Transplantation will provide an interface for health authorities and the general public to access data on donation and transplantation practices and legal frameworks. It is also intended to be used as a work and information exchange tool for the people responsible for the area of transplants from countries and regions and work groups who take part in The Transplant Worldwide Network.

The GODT portal will provide two kinds of access:

- The general public will have access to general information, published documents and activity data on donation and transplantation.
• Authorized users will have a password to access a restricted area with work documents and the survey to be filled in.

The GODT web site contains the World Transplant Registry, a database where information will be collected from regions and countries. A specific survey has been designed that includes questions on:
• Organizational systems for transplantation (for organs, cells and tissues)
• Legislation for transplantation (for organs, cells and tissues)
• Updated transplantation data from each country (about organs, cells and tissues).

These data will be public. It will also include general information about transplantation and donation:
• Newsroom: information about events and press releases or media information.
• Become a donor: videos and media campaigns and other documents.
• The library: technical or scientific documents and guidelines.
• Links: Selection of web sites from National Transplants Organizations, Transplant Societies Journals, Information about Transplant, Registries and other.