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Establishment of a multinational global registry - Extrapolation to ASTREG

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Registries The importance of registries in the field of organ donation and transplantation has been already highlighted by some relevant documents. In 2004 the World Health Assembly (WHA) adopted the Resolution WHA57.18 that requested to continue examining and collecting global data on the practices, safety, quality, efficacy and epidemiology of allogeneic transplantation and on ethical issues, including living donation. This request was reiterated in 2010, through Resolution WHA63.22. Also, the World Health Organization (WHO) Guiding Principles on Human Cell, Tissue and Organ Transplantation state in Guiding Principle number 10, that the long-term outcomes of cell, tissue and organ donation and transplantation should be assessed, and the level of safety, efficacy and quality of human cells, tissues and organs for transplantation, as health products of an exceptional nature, must be maintained and optimized on an ongoing basis. Ideally the national registries should be an initiative from the National Competent Authorities because this sort of registries are needed for the adequate oversight of practices of donation and transplantation, although in some settings the professionals or the professional societies play an important role in the development of such registries. In those situations it is important to find ways of cooperation. There are some steps to follow when developing a registry:

- Define goal and /or purpose and the scope
- Set the registry team & governance
- Define the data set (minimal data vs expanded data)
- Set the functioning rules
- Communication and dissemination

A step forward in the development of national registries is the contribution to international data collection. That is important for several reasons: the international registries are useful to increase the dataset and to be able to explore certain aspects that we would not be able to explore on our own; international registries allow international comparisons, hence benchmarking, and they allow covering international aspects such as the movements of donors and recipients across different jurisdictions. Bearing in mind all these aspects, special attention is paid on the Global Observatory on Donation and Transplantation (GODT)

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(<http://www.transplant-observatory.org/>). In addition to the above mentioned WHA Resolutions, the United Nations Resolution 71/322 particularly states the relevance of participating with national data in the GODT. **The Global Observatory on Donation and Transplantation (GODT):** The GODT is developed and supported by the National Transplant Organization of Spain as a Collaborating Center of WHO. This global database basically compiles country descriptions of legislations and regulatory oversights in place, and also the annual activity data on organ donation and transplantation across the world. The material and methods of the GODT are well established. Annually, a standard questionnaire is used for the collection of country specific information on legislation and organization programmes in the field and organ activities (donation, transplantation and waiting list) as aggregated data. The questionnaire is completed by individuals officially designated by the corresponding Ministries of Health or by identified health authorities. Every year, a global report is produced as a core function of the GODT, in which, aggregated data on donation and transplantation of WHO Member States are compared by country, but also at WHO regional level. Monitoring donation and transplantation trends is key to support countries in generating evidence- based policies and strategic plans. The table 1 shows the countries with registries on socio-demographic, clinical and /or epidemiological data of the donors (living or deceased) and existing follow-up registries of transplants recipients and living donors. Those countries belong to the WHO regions of South East Asia (SEAR) and the Western Pacific (WPR). Such information has been extracted from the 2020 Global Report of the GODT. When analyzing the WHO regional data we can observe that SEAR and WPR present lower rates in the number of organ donations and also in the number of transplants per million population than other WHO regions. The data derived from the GODT provides valuable information that may help to identify areas of improvement. **Conclusions** The GODT is the most comprehensive source to date of worldwide data officially reported by countries on donation and transplantation. Participating in this global data collection allows the engagement of Member States to annually report reliable data. It is essential for benchmarking and essential to ensure transparency of practices in our field.

Table 1. Availability of different types of donor and transplant registries among countries belonging to the WHO regions of South East Asia and Western Pacific.

	Donors' Registries		Recipients Follow up / outcomes registries					Living Donors Follow up registries		
	DD registries	LD registries	Kidney	Liver	Heart	Lung	Pancreas	KidneyLD	Liver LD	Lung LD
Australia	√	√	√	√	√	√	√	√	√	
China	√	√	√	√	√	√		√	√	√
India	√	√	√	√	√	√	√	√		
Iran	√	√	√	√	√	√	√	√	√	√
Japan	√	√	√	√	√	√	√	√	√	√
Malaysia	√	√	√	√	√	√		√	√	
Mongolia	√	√	√	√				√	√	
Philippines	√	√	√	√				√	√	
Rep of Korea			√	√	√	√	√	√	√	√
Singapore	√	√	√	√	√	√	√	√	√	
Sri Lanka	√		√	√	√	√	√			
Thailand	√		√	√	√	√	√	√	√	

DD registries: Deceased Donors' registries; LD registries: Living Donors' registries; LD: Living Donor
Blank fields: Not available information/not applicable or not registries in place