

The role of the Institute of the Republic of Slovenia for the transplantation of organs and tissues Slovenija – transplant in the donor program

Petra Lušicky, Danica Avsec

Institute of the Republic of Slovenia for the Transplantation of Organs and Tissues, Ljubljana, Slovenia

**Korespondenca/
Correspondence:**

Petra Lušicky, e: petra.lusicky@gmail.com

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Abstract

Organ transplantation has become an established method of treatment of organ failure. In some cases, it represents the only effective treatment.

With the accelerated development of transplant medicine in the world, three main models of organ donation and transplantation have been established – the Spanish, the American and the mixed model. Slovenia's organisational aspect of organ donation and transplantation followed the Spanish model. The Institute of the Republic of Slovenia for the Transplantation of Organs and Tissues – Slovenia Transplant – became operational in 2002. Organ procurement and transplantation are intertwined in a national network, which consists of 11 donor hospitals, the transplant centre and the centre for tissue typing. The most important segments of the donor programme are donor hospitals with hospital transplant coordinators, while central transplant coordinators are responsible for coordinating the activities at all levels. Slovenia Transplant ensures effective execution of the donor programme and the quality and safety of procured organs and tissues. It issues professional guidelines and provides expert supervision. Special attention is devoted to the education and training of healthcare professionals at all levels of healthcare system and raising awareness of the general public.

The number of deceased donors in Slovenia has been rising since 1998. In terms of the number of actual deceased donors per million population and the family refusal rate, our achievements are comparable to those in other European and other countries, thus indicating a high level of trust in the donor program and in the Slovenija Transplant as an institution.

The future of the donor programme lies in progressive ethical codes and guidelines that treat palliative care or end-of-life care patients as possible deceased donors. In Slovenia, an initiative has already been taken to include such approach in the ethical code.

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1 Introduction

Organ transplantation is a well-established treatment option for a number of patients with chronic failure of target organs. Organ transplantation represents the only effective treatment option in patients with end-stage liver, lung and heart failure and can significantly improve the quality of life in patients with kidney and pancreas failure. Transplant activities began to develop in the early twentieth century and soon organ donation programmes were initiated.

The beginnings of donor and transplantation activities in Slovenia date back to 1969, when a Tissue Typing Centre was set up in the Blood Transfusion Centre of the Republic of Slovenia. As a result, in 1970 the first successful living donor kidney transplantation was carried out in the University Medical Centre (UMC) Ljubljana (1,2).

The first national transplantation law in the former Yugoslavia came into force in 1985 and was followed by the Brain Death Determination Act the following year. These legal instruments opened the door to organ transplantation from deceased persons. In 1986, the first successful deceased-donor kidney transplantation was performed in the UMC Ljubljana. Successful pancreas and heart transplantations followed in 1990, a liver transplantation in 1995 and a lung transplantation in 2003 (1,2).

With the accelerated development of organ transplantation there emerged the need for improved organisation and control of organ donation and transplantation services. 1992 is a turning point in the development of organ donation services in Slovenia: it marks the beginning of activities carried out by the national transplant coordinator and the setting up of the transplantation expert advisory committee. The first deceased

donor was successfully prepared for the transplantation procedure the same year in Maribor. On the request of the Health Insurance Institute of Slovenia in June 1993, an expert report on the establishment of the Institute of the Republic of Slovenia for the Transplantation of Organs and Tissues and national organ transplantation network was prepared. It defined the scope of work of the institute, described in detail the national organ donation programme, identified the reasons for shortage of organs for transplantation and proposed possible solutions to this issue. In the report, close links with donor hospitals and coordination of organ donation programme were identified as the fundamental requirements for successful implementation of the organ donation and transplantation programme. Also, it described the tasks and duties of the coordination service, the national transplant coordinator and the transplant coordinator on call (1,2).

In 1997, a 24-hour organ transplantation coordination service was established and one year later the national transplantation network was set up. The same year the coordination service was renamed to the Transplant Centre, run within the Division of Surgery, UMC Ljubljana (2,4)

Early on, the Slovene pioneers in the field of organ transplantation recognised the importance of educating health-care providers and other target groups to enhance further development of this service. As early as in 1993 the first training course in brain death determination was held for ICU physicians. In order to meet the need for further education regarding the procedures of brain death determination and management of potential organ donors, the international meeting "Organ transplantation – a mo-

dern treatment modality” was organised in Maribor. It was followed by several national and international training courses (5).

Organisational structure of transplantation services kept improving over the years. The national institute for organ and tissue transplantation, called Slovenia Transplant (ST), which served as a national liaison institution, began to function independently in 2002. A cooperation agreement between ST and the Eurotransplant (ET) international foundation was signed in 2003, although the requirements for full membership in the international ET transplantation network had been met as early as 2000. This was the first cooperation agreement signed by the UMC Ljubljana and ET (1-3,6,7).

2 A brief overview of the characteristics of organ donation and transplantation models in the world

With the accelerated development of transplant medicine in the world, three main models of organ donation and transplantation were established: the Spanish, the American and the mixed model, each with its specific characteristics (8). The mixed model is also called the European model, as it has been adopted by the majority of European countries. The Directive 2010/53/EU (hereinafter the Directive) has also laid down some key rules for EU countries (9).

The main principles of the Spanish model, adopted by the Directive, refer to the creation and application of relevant national legislation, coordination of organ transplantation services at the local, regional and national levels, founding of a central body responsible for supervisi-

on, guidance and support of hospital organ donation and transplantation activities, continuous education and training of health professionals involved in organ donation and transplantation, effective media liaison, education of the general public, and remuneration of hospitals providing organ donation and transplantation services (8).

Hospital transplant coordinators, who play a key role in the organ donation and transplantation process, are usually physicians (8) assisted by nursing staff (8). The model has proved very effective and most of its principles have been adopted by a number of countries, including Slovenia, Portugal, Italy and Spanish- and Portuguese-speaking countries of Central and South America (10-14). The main principles of the Spanish model were incorporated into the organ donation and transplantation models of Croatia, Australia, Great Britain and Ireland (15-20).

The American model is based on the services provided by 58 non-profit organ procurement organisations (OPOs). A great majority of these are privately owned; these services are provided only in a few hospitals. Every OPO is active within its assigned area and is responsible for recruiting new registered donors, as well as for the donor process coordination. Under the federal law, all OPOs should be included in the Organ Procurement and Transplantation Network (OPTN), established by the U.S. Department of Health and Public Services. OPTN is a private-public partnership that links all professionals involved in the U.S. organ procurement and transplantation system. The national network is administered by the non-profit organisation United Network for Organ Sharing (UNOS). Every OPO employs organ procurement coordinators. This role is filled by registered nurses, paramedics and

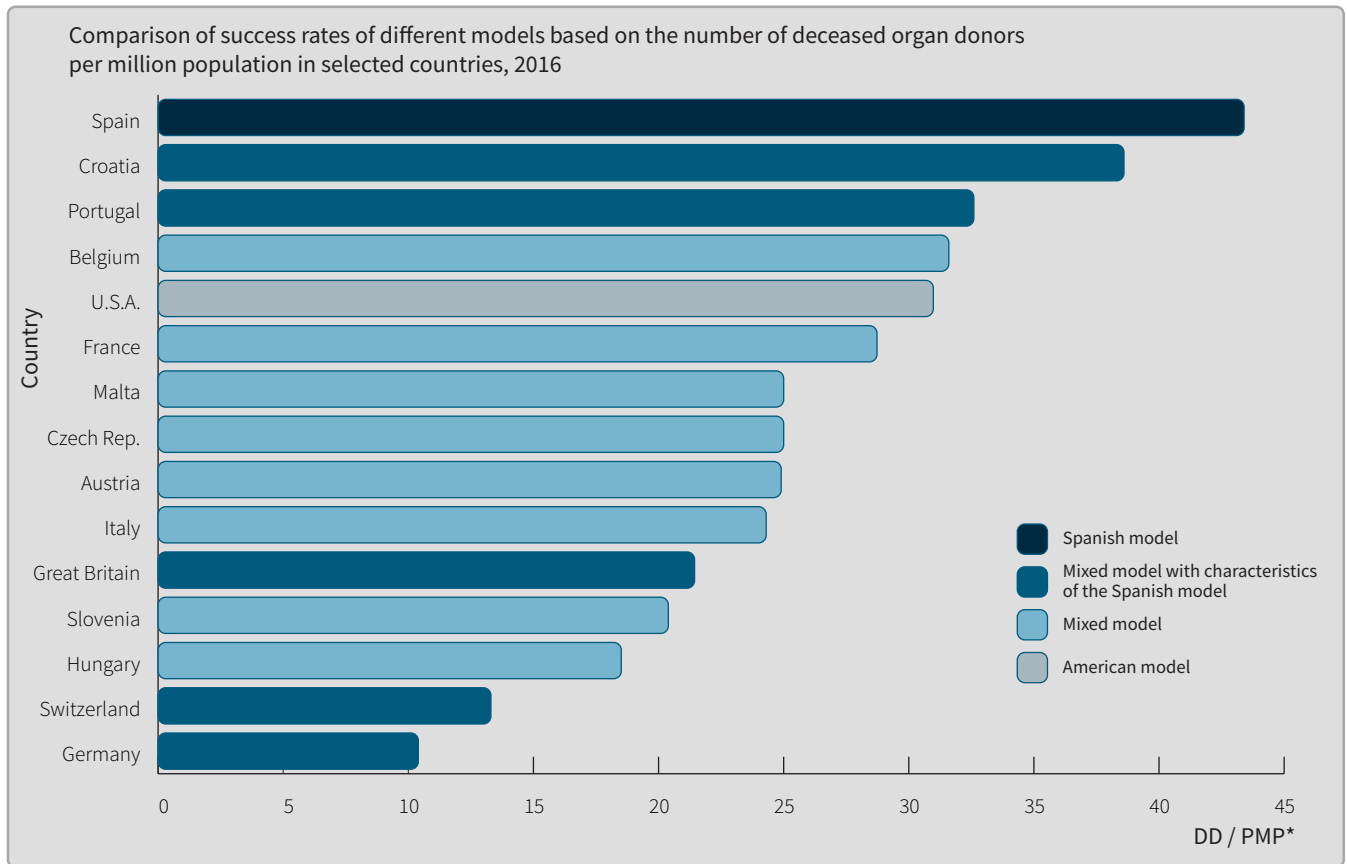


Figure 1: Graphical representation of success rates of individual organ donation and transplantation models in selected countries based on the number of deceased donors per million population (DD/PMP) in 2016 (30,31).

*number of deceased donors per million population

other healthcare professionals. When they are notified that a potential deceased donor has been identified, they travel to the hospital to evaluate the suitability of the deceased for donation. They are responsible for evaluating potential donors, for speaking to the family about consenting to organ donation, donate, and are responsible for the management of the donor until transplantation can and for the coordination of organ removal and transport (21-23). The American model of organ donation and transplantation has been adopted by Japan (24). The most important difference between the Spanish and the American model is that in the former donor activities are organised in hospitals. Activities related to organ donation are directly linked to other hospital services, while in the

American model all coordination activities take place outside hospitals.

Most European countries decided to use the so-called mixed (European) model of organ donation and transplantation. The organisational pattern of these services in Austria, Switzerland, France, Island and Canada (25-29) varies according to the country specificities, which may give the impression that it is unique to each country. Yet, they all share some characteristic features of the Spanish model.

The success rate of each donor model depends on different elements and can be objectively evaluated by the number of deceased donors per million population. Spain has successfully integrated individual components into a comprehensive model of organ donation and

transplantation (30). All countries face long waiting lists and shortage of donor organs. Creating a system that would meet patients' needs is a challenge shared by all countries (Figure 1).

3 Legislation and organisational structure of organ donation and transplantation services in Slovenia

In Slovenia, the national organ donation and transplantation system was developed based on the main principles of the successful Spanish model. According to the decision of the Government of the Republic of Slovenia and as stated in the Directive, in 2002 a central liaison body, the Institute of the Republic of Slovenia for Organ and Tissue Transplantation – called Slovenia Transplant (ST) – began operating independently as a central authorised institution for organ donation and transplantation activities.

In compliance with the constituent act of foundation, ST is financed by the state budget and some other sources. In accordance with the Act on Procurement and Transplantation of Human Body Parts for Therapeutic Purposes, the Ministry of Health of the Republic of Slovenia is authorised to give approval or –in case of non-compliance with conditions – withdraw approval to organ and tissue procurement and transplantation for donor hospitals and transplant centres (32,33).

The Act on Procurement and Transplantation of Human Body Parts for Therapeutic Purposes harmonises the standards of quality and safety of human organs intended for transplantation with the Directive. Article 40 defines the responsibilities of ST (9,32), which include: ensuring transparency

and traceability of services and providing professional control of quality and safety of organs in donor hospitals and transplant centres. ST prepares professional guidelines and provides support to all healthcare professionals involved in organ transplantation (32). It designates competent persons authorised to recruit individuals to donate organs after death; it supervises organ exchange between EU member states and third countries and offers training and awareness-raising programmes for healthcare professionals and other target groups (32,33).

In addition, ST manages and promotes the expansion of the information system for procurement, transplantation and disposal of organs and tissues; it manages the system of notification of serious adverse events and reactions and takes appropriate actions when required. ST operates a central organ donor and recipient registry, participates in the upgrading of the registry of non-related organ bone marrow donors, keeps records of donor and transplantation centre activities. Furthermore, it sets up and runs the system of the assignment and use of donor national identification number (32,33).

Different types of transplant coordinators involved in donor and transplantation activities work in close collaboration with ST. Hospital transplant coordinators, who work in all donor hospitals, are nominated for the position by the donor hospital and approved by the Minister of Health in agreement with ST. Hospital transplant coordinators must be physicians with long-term experience in organ transplantation (32-34). Central transplant coordinators coordinate activities related to organ donation and transplantation performed in donor hospitals, transplant centres and Eurotransplant. Tasks and responsibilities of clinical transplant coordinators,

Table 1: The Madrid Resolution on Organ donation and Transplantation: Classification of possible and actual deceased donors by severity degree, procedures and definitions (6,35).

Possible deceased organ donor Patient with a devastating brain injury OR patient with circulatory failure AND apparently medically suitable for organ donation		
Donation after circulatory death (DCD)	Reasons why a potential donor does not become a utilised donor	Donation after brain death (DBD)
Potential donor (DCD)	System of work	Potential donor (DBD)
<ul style="list-style-type: none"> A person whose circulatory and respiratory functions have ceased, and resuscitative measures are not to be attempted or continued; A person in whom the cessation of circulatory and respiratory functions is anticipated to occur within a time frame that will allow organ recovery. 	<ul style="list-style-type: none"> Failure to identify/ refer a potential or eligible deceased donor; Brain death (BD) diagnosis not confirmed or completed; Circulatory death not declared within the appropriate time frame; Logistical problems; Lack of appropriate recipient. 	A person whose clinical condition is suspected to fulfil the criteria of brain death.
Eligible donor (DCD)	Donor/organ	Eligible donor (DBD)
A medically suitable person who has been declared dead based on the irreversible absence of circulatory and respiratory functions as stipulated by the law of the relevant jurisdiction, within a time frame that enables organ recovery.	<ul style="list-style-type: none"> Medical unsuitability; Haemodynamic instability/ unanticipated cardiac arrest; Anatomical, histological and/or functional abnormalities of organ; Organs damaged during recovery; Inadequate perfusion of organs or thrombosis. 	A medically suitable person who has been declared dead based on neurological criteria as stipulated by the law of relevant jurisdiction.
Actual donor (DCD)	Consent to donation	Actual donor (DBD)
Consented eligible donor: <ul style="list-style-type: none"> In whom an operative incision was made with the intent of organ recovery for the purpose of transplantation, OR From whom at least one organ was removed for the purpose of transplantation. 	<ul style="list-style-type: none"> Expressed intent of deceased not to be donor; Relatives' refusal to give permission for organ donation Refusal by coroner or other judicial officer to allow donation for forensic reasons. 	A consented eligible donor: <ul style="list-style-type: none"> In whom an operative incision was made with the intent of organ recovery for the purpose of transplantation, OR From whom at least one organ was recovered for the purpose of transplantation.
Utilised donor (DCD)		Utilised donor (DBD)
Actual donor from whom at least one organ was transplanted.		An actual donor from whom at least one organ was transplanted.
The dead donor rule must be respected. That is, patients may only become donors after death, and the recovery of organs must not cause the donor's death.		

who are selected from among the transplant centre health professionals and are appointed by the transplant centre, include organising organ recipient management, listing the patients on the waiting list, updating waiting lists, ensuring that potential recipients have regular medical examinations and that potential recipients are well prepared for a possible organ transplant (3,32).

4 Organ donation activities in Slovenia

Classification of potential organ donors according to the stage and definition of the potential donor is provided by the Madrid Resolution on Organ Donation and Transplantation, as indicated in Table 1 (35). There are two ways of donating and procuring organs

after death: donation after brain death and donation after circulatory death. In Slovenia, organs can be procured only from brain-dead donors, yet donation after circulatory death is a well-established transplantation policy in many European countries, such as Spain, Great Britain, Austria, the Netherlands, France, Switzerland and Estonia.

All activities related to organ donation and transplantation in Slovenia are intertwined in a uniform national network, which comprises 11 donor hospitals, the Transplant Centre in the UMC Ljubljana, and the Tissue Typing Centre (3,32).

ST is a liaison institution in this network: It harmonises the activities of all national institutions and Eurotransplant. It coordinates the services provided by transplant coordinators and the activities related to procurement, transplantation and disposal of organs and tissues and ensures 24/7 availability of central transplant coordinators (3,7,33). ST acts in accordance with the guiding principles on cell, tissue and organ transplantation, laid down in special documents of the WHO, Council of Europe, European Parliament and European Commission (36-38). These principles include altruism, non-profitability, professionalism, efficiency, ethics and transparency (36-38).

A lot of effort has been made to develop a national organ donation network, whose aim is to enhance activities related to organ donation, to increase the number of organs available for transplantation and to increase the potential for deceased organ donation. Efforts are also directed to the development of a supplementary programme of living organ donation. The aim of these programmes is to make organ transplantation for therapeutic purposes accessible to all Slovene citizens (4,32).

Hospital transplant coordinators are responsible for the development and execution of donor programme in their respective regions. Their tasks include: identifying potential deceased donors, conducting family interviews for organ donation consent and coordinating organ donation tasks in collaboration with central transplant coordinators (6,32,33).

At the donor hospital level, special attention is devoted to assuring high quality of all organ donation activities carried out in healthcare institutions involved in this process (32,33).

4.1 Donor hospitals

Activities of donor hospitals are carried out in accordance with the agreement and contract made with ST. At present, the following 11 donor hospitals are active in the donation programme: UMC Ljubljana, UMC Maribor, Celje General Hospital, Murska Sobota General Hospital, Dr. Franc Derganc General Hospital in Nova Gorica, Izola General Hospital, Dr Jože Potrč General Hospital in Ptuj, Novo mesto General Hospital, Slovenj Gradec General Hospital and Jesenice General Hospital (4). Recently, the Brežice General Hospital has joined the network and is now going through the necessary formalities. Tasks and duties of donor hospitals are listed in the Act on Procurement and Transplantation of Human Body Parts for Therapeutic Purposes and in the collaboration agreement (32).

4.2 The procedures in the organ donation and procurement chain

The process of organ donation and procurement involves a series of interconnected tasks, constituting the so-called organ donation and procurement

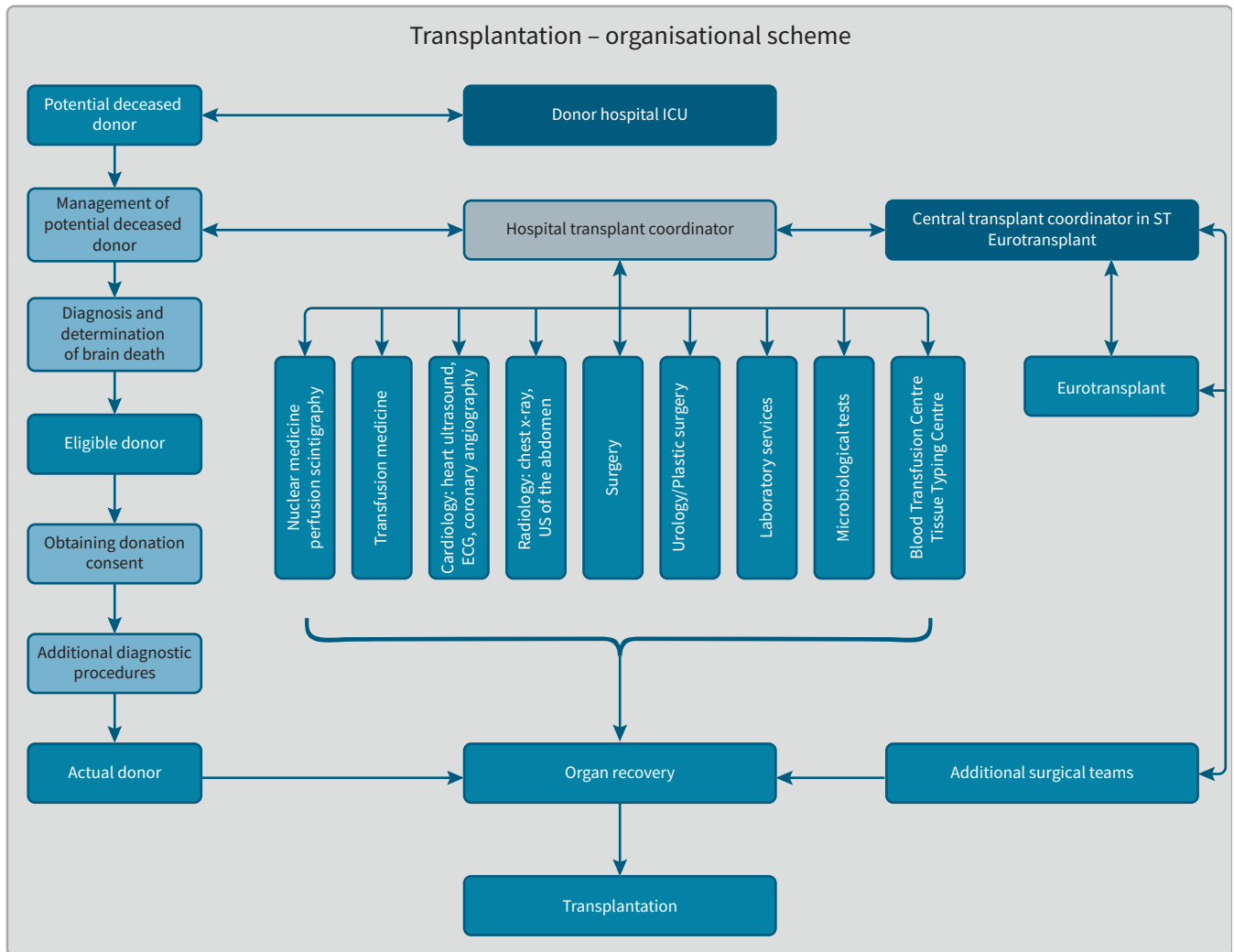


Figure 2: Proposed organisational scheme of organ and tissue donor management in a donor hospital: based on the Maribor General Hospital Organisational Chart defining procurement procedures in deceased donors, and on the Madrid Resolution on Organ Donation and Transplantation (35,42).

chain. The responsibilities of donor hospitals are listed in Table 2. The sequence of procedures depends on the clinical situation; each procedure can be interrupted at any stage of the process.

The first step in this activity chain is routine identification of potential deceased donors. This task is performed by the hospital transplant coordinator jointly with the ICU staff. Simultaneously, determination of brain death is performed in accordance with the neurological criteria as stipulated by the law. Evaluation for brain death should be considered in patients who have suffered severe

mechanical head injuries, intracranial bleeding, ischaemic stroke, malignant intracranial tumours, acute hypertensive hydrocephalus, hypoxic-ischaemic brain injury after cardiac arrest or prolonged circulatory shock. A patient declared to be brain dead is considered a potential deceased donor and is classified as an eligible organ donor according to the Madrid Resolution on Organ Donation and Transplantation (Table 1) (4,6,35). The second step in the chain of donor activities is a family interview for donation consent. The interview is conduct-

ed after whether the patient is a registered organ donor listed in the national registry. It is desirable that the interview regarding organ donation is conducted by both the treating physician and the hospital transplant coordinator. The treating physician, who has developed a bond of trust with the deceased patient's relatives during treatment, addresses the issue of death, while the role of the hospital transplant coordinator is to discuss possible organ donation (39,40).

Healthcare professionals need adequate training to be able to effectively and competently perform this interview (40). They should know that the deceased person's consent to donate organs and the consent obtained from the patient's family play a key role in the process of organ donation. They should be attentive to the interview dynamics and should give sincere answers to questions of the deceased person's relatives. Although the interview is conducted in a proactive manner, influencing the interviewees' opinion should be avoided. If the deceased's family cannot come to a prompt de-

cision, they should be informed that the time available for their decision making is limited, but that they can nevertheless take some time to think about their decision (41).

Once the deceased person's relatives have consented to donation, the potential donor's eligibility for organ donation is assessed. This responsible and complex task is carried out after the consultation with experienced specialists or authorised physicians in ST (6,33,34). The final decision on the suitability of the organ for transplantation is provided by the potential recipient's treating physician.

Other tasks of donor hospitals in the process of organ donation include: maintaining functions of the eligible donor's organs according to the hospital protocol, organising multi-organ retrieval and providing the required documentation.

An exact organisational scheme, including all phases, from potential donor detection to organ recovery, should be drawn up to ensure effective execution of the programme (Figure 2) (5,42).

Tabela 2: Povzetek nalog donorskih bolnišnic.

Tasks of donor hospitals	
Identification	Routine detection and identification of potential deceased donors
Reporting	Notifying hospital transplant coordinator about possible deceased donors
Brain death determination	Diagnostic procedures to confirm brain death based on neurological criteria as stipulated by the law
Family interview	Interview for organ donation consent
Management of the donor	Performance of procedures to maintain function of the donor's organ
Donor evaluation	Evaluation of organ donor eligibility
Organ recovery	Organisation of organ removal
Organisation of donor hospital	Functional organisation of the donor hospital, preparation of organisational plan, assignment of authorised healthcare professionals
Documentation	Accurate filing of donor documents and organ procurement procedures

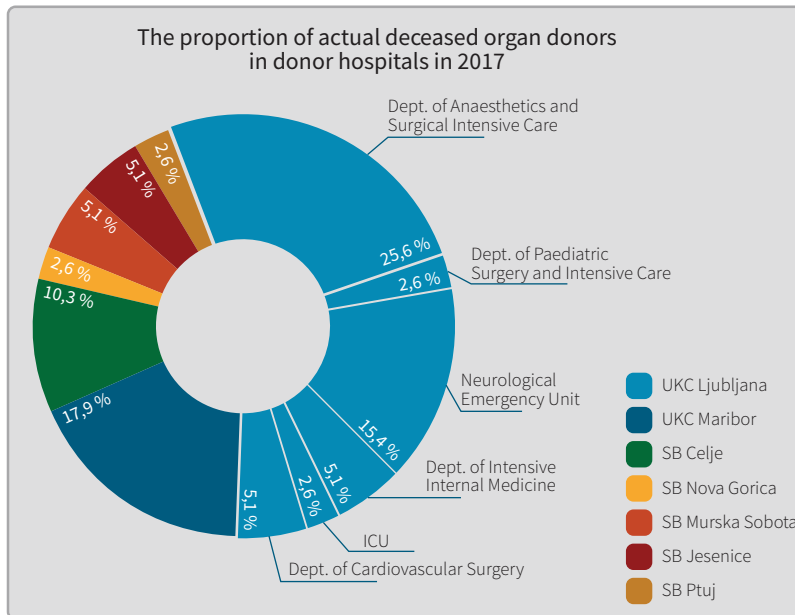


Figure 3: Graphical representation of the proportion of actual deceased donors in donor hospitals in 2017.

4.3 Organ donor service in Slovenia in 2017

Since 1998, the number of deceased organ donors in Slovenia has been increasing. In 2017, consent was obtained for 44 persons eligible to donate, of whom 39 became actual donors (i.e. 18.9 deceased organ donors per million inhabitants) (Figure 3). In 2017, Central ICU, UMC Ljubljana, obtained the highest consent rate for organ donation - 11 deceased donors (Figure 4). The rate of deceased donors recorded in 2017 in Slovenia equals the average rate in other Eurotransplant member countries (Figure 5) (7).

An increased number of deceased organ donors is recorded in parallel with a low refusal rate for organ donation (4). The latter has been decreasing since 2013 (Figure 6) and is relatively low as compared to the rate documented in most EU countries (43-45). In 2017, the refusal rate was 16 %, i.e. the lowest in the past six years. A very low proportion of refusals of consent for organ donation was noted in 1999 as well, yet the figures are not re-

liable because before 2000 refusal rates were not accurately recorded.

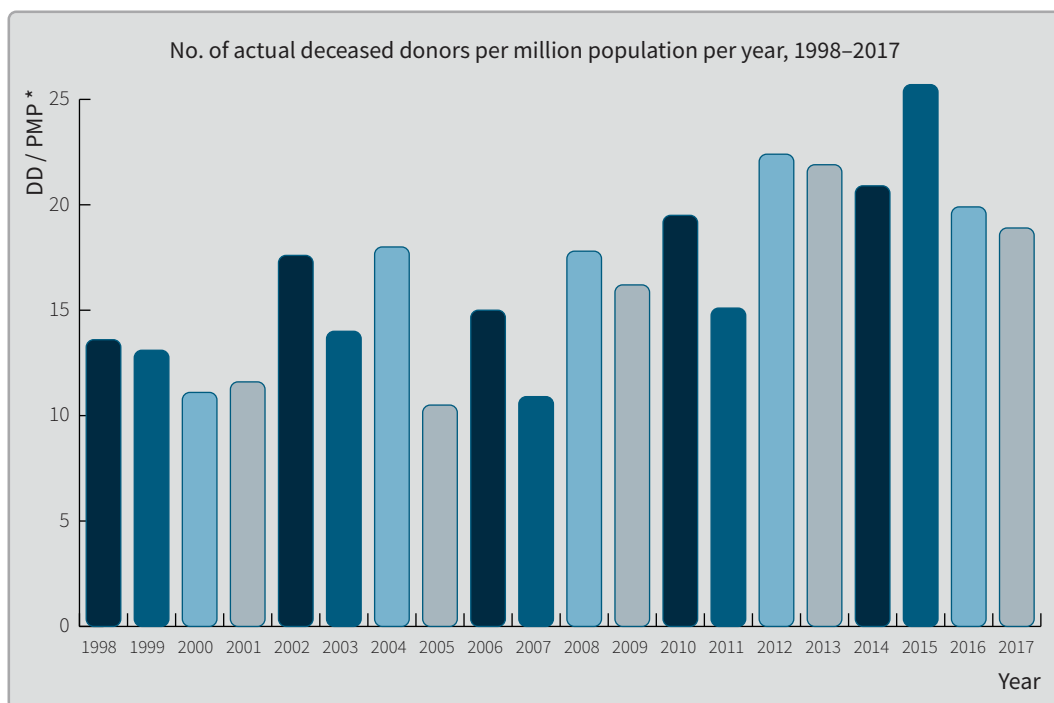
4.4 Efficiency of the donor programme implementation

The process of organ procurement has several phases. Each of them requires great commitment to the process, responsibility and in-depth knowledge of the entire procedure.

In order to improve the efficiency of organ donation activities, the European Union set up the ACCORD (Achieving Comprehensive Coordination in Organ Donation throughout the European Union) project. It was conducted in the EU countries, with active participation of Slovenia, from May 2012 to November 2015. The main objectives of ACCORD were to improve and strengthen the potential of EU member countries in the area of organ donation and transplantation, to improve mutual cooperation and to incorporate provisions of the Directive into the national law (46).

A study conducted within the ACCORD project in 2013 showed how many potential organ donors can be lost in individual stages of the process (Figure 7) (47). Two Slovene donor centres, UMC Maribor and Dr. Franc Derganc General Hospital in Nova Gorica, participated in the study.

The donor process in the study was slightly simplified to make it easier to understand. The study included all patients who died in the ICU, i.e. a total of 1,670 deceased persons. A retrograde analysis of the course of treatment showed that 16 % of the patients who were enrolled in the study at the moment of death or after the decision to withdraw active treatment has been made, were not mechanically ventilated. Mechanical ventilation is a key procedure in the process of organ procurement and donation, the-



Slika 4: Graphical representation of the number of actual deceased donors per million population (DD/PMP) in Slovenia per year, 1999–2017.

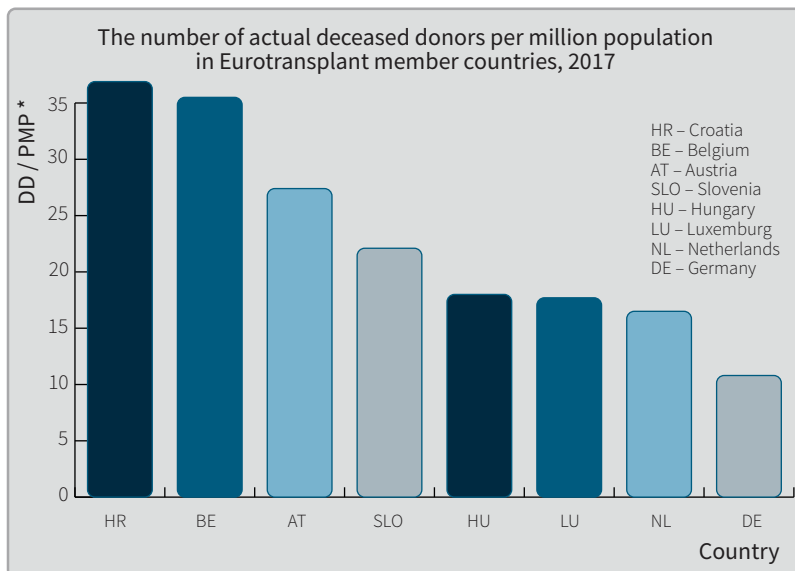
* No. of actual deceased donors per million population

refore donor detection was not possible in 16 % of the deceased patients. Further 48 % of the patients, i.e. 673 patients, suffered devastating brain injury and their clinical condition indicated the possibility of meeting the criteria for brain death. Diagnostic tests to determine brain death were not performed in 21 % of the patients, which represents a loss of further 153 potential deceased donors. Transplant coordinators were not notified of 16 potential deceased donors, i.e. 3 % of potential deceased donors. These data should be interpreted with caution, because in some countries transplant coordinators are notified about all possible and potential organ donors, while in others they are informed only of patients in whom brain death has been confirmed or active therapy has been discontinued. Organ donation was discussed with families of only 46 patients, i.e.

9 % of the remaining possible deceased donors. In 24 % of cases, the relatives refused to give consent to organ donation, which accounts for 114 eligible deceased patients lost to donation. Organ donation was accomplished in solely 19.3 % (one-fifth) of the 1,670 available potential deceased donors (47).

The study has clearly identified the weaknesses of the process at different stages and identified the key interventions necessary for realising the full potential for organ donation. In Slovenia, regular assessments of the donor process efficiency are made to ensure that each individual step and task in the process is implemented to its full potential.

These data emphasise the importance of high-quality execution of individual steps of the donation process for the efficiency of the donor programme and its key role in preventing a decrea-



Slika 5: Grafični prikaz števila dejanskih umrlih darovalcev na milijon prebivalcev (MD/PMP) v letu 2017 v primerjavi z ostalimi članicami mednarodne fundacije Eurotransplant (7).

*Število dejanskih umrlih darovalcev na milijon prebivalcev

se in the pool of potential organ donors. Solutions indicated by the study accord with those listed below.

5 Assessment of the efficiency of hospital donor programme implementation

Since 2011, the Quality Assurance Programme (QAP) in organ and tissue donation has been implemented in all donor hospitals. All patients who died in the ICU are recorded in the programme by the hospital transplant coordinator. The main aim of this programme is to improve the efficiency of the donor programme and reduce risks for potential loss of deceased donors. The programme enables monitoring of the efficiency of the donor programme execution in ICUs and helps detect possible process breakdowns and obstacles to the implementation of donor activities (6).

With the help of the program an internal audit is performed every three months by the hospital transplant coordinator in order to evaluate the donor programme efficiency. The audit report lists all deceased patients with confirmed brain death, all potentially brain-dead patients and the reasons for consent or refusal to donate organs (7).

ST performs an annual external audit on the quality of the donor programme based on the internal audits. The audit is focused on the detection and analysis of cases which represented missed opportunities for transplantation despite appropriate medical indications for organ donation, as well as on missed brain death cases, and patients in whom brain death diagnostics was not performed for a variety of reasons. The analysis addresses timeliness of potential deceased donor detection, appropriateness of brain death determination procedures, and consistency of the donation and transplantation process implementation with the latest guidelines and protocols. ST forwards the results of external audit to directors of donor hospitals, hospital transplant coordinators and the responsible ICU healthcare staff. Possible improvements and solutions are discussed and agreed on by all involved parties (6).

Concurrent with internal and external audits, QAP allows the identification of weaknesses of all phases of the donation process, from potential deceased donor detection and brain death determination to organ and tissue recovery (6). Analysis of the donor programme efficiency showed that the rate of unrealised donor potential is as high as 50 %. Implementation of every single step in the donation process requires good organisation, solid knowledge of the donor programme, awareness of the importance of organ donation and appointment of responsible personnel with clearly

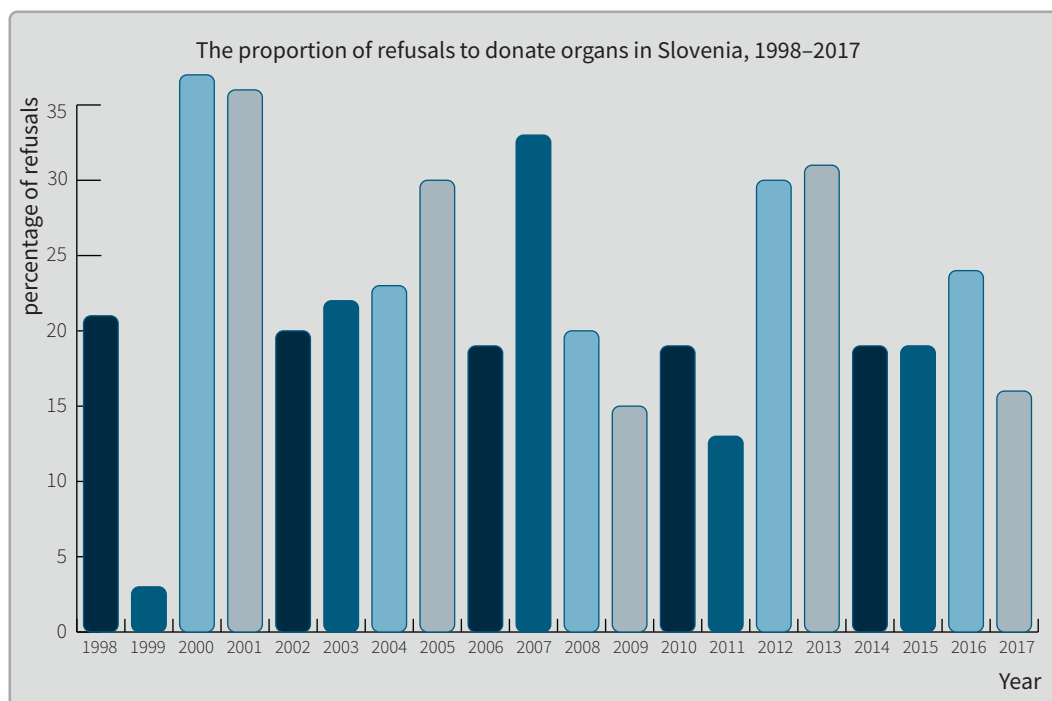


Figure 6: Diagram showing the proportion of family refusals to consent to donation in Slovenia per year, 1998–2017.

defined tasks and duties. In addition to donor and transplant coordinators, each ICU should designate a physician to assume responsibility for the development and implementation of organ donation and transplantation programmes.

6 Training and awareness-raising programmes for healthcare professionals and other target groups

Education and awareness-raising among health professionals and other target groups are key factors for successful development of the donor and transplantation programme and represent the main tasks performed by ST. In February 2016, Rules on the programme curriculum and training in organ procurement procedures (48) came into force.

6.1 Training and awareness-raising programmes for healthcare professionals

ST provides various education programmes on donation and procurement of human body parts and tissues for therapeutic purposes, intended for healthcare professionals.

For several years, basic training programmes have been offered to healthcare professionals who are directly or indirectly involved in the process of organ donation and transplantation. The aim of this training is to further their professional knowledge and acquaint them with basic principles governing donation and transplantation of organs and tissues in Slovenia. The training course is carried out in collaboration with the Spanish Donation and Transplantation Institute. It features lectures and workshops devised for small groups of participants and

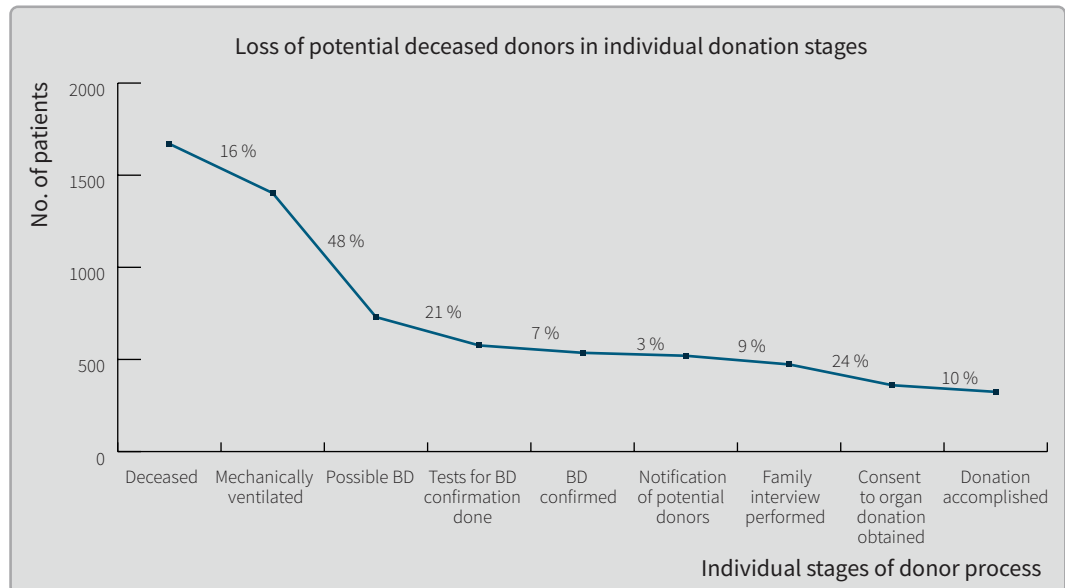


Figure 7: Graph: results of the ACCORD study, which analysed the likelihood of potential donor loss in individual phases of donor process (47).

is led by experienced transplant physicians and their co-workers active in organ donation (49,50).

Targeted and extended training programmes are intended for healthcare professionals and their collaborators in hospital units providing donation and transplantation services. These training programmes follow the guidelines of the uniform European training programme ETPOD (European Training Programme on Organ Donation). It was created by a group of internationally recognised experts, including professionals from Slovenia. The programme features five sets of lectures, case reports and workshops run by physicians and other healthcare providers active in the process of organ donation and transplantation (49,51). Workshops on breaking bad news are also held, on a regular basis. They are intended for healthcare professionals in donor centres and ICU units and for transplant coordinators. The training programme is focused on mastering emotional responses and in-

terpersonal communication skills. It is delivered through lectures, tutorials and role-playing with a professional actress, with whom participants are taking on roles of healthcare providers and family members (41,49).

6.2 Training and awareness-raising programmes for other target groups.

ST is committed to education, information dissemination, awareness raising in other target groups and organisation of events using traditional and modern social media to meet specific needs of this area of expertise (52).

To this purpose, ST prepares and publishes various publications, such as annual reports, manuals and promotional materials (49,52). The book “The development of transplant medicine in Slovenia: programmes, guidelines and perspectives”, published in 2016, provides a comprehensive presentation of transplantation medicine and donor

programme activities in Slovenia. Every year, various events intended for professionals and general public are organised to mark the international Organ Donation Day (49,53).

Various media, organisations and societies are important partners in raising the general public's awareness on organ donation. High-profile campaigns have been run in cooperation with the Union of Professional Footballers, the Maribor Football Club, the Radio Television Ljubljana, the Slovene Red Cross and the AV Studio marketing agency (32,52).

ST provides regular training programmes tailored to the needs of various interested public groups, including students from different universities, the Red Cross, and the Rotary and Lions clubs. Likewise, education is offered to individuals authorised to obtain statements of consent to organ and tissue donation for transplantation after death (32,49,52). In collaboration with Draga Potočnjak, ST participated in writing a script for the theatre performance *The Heart in the Palm of the Hand* directed by Marko Bulc, which took place in the Ljubljana City Theatre in 2014. This play succeeded in familiarising the general public with the issue of organ donation and transplantation in a unique way (32).

ST takes part in various studies and projects dealing with organ and tissue donation and transplantation. Since 2016, a joint research project on social marketing has been conducted by ST, the Faculty of Social Sciences, University of Ljubljana and the National Institute of Public Health to explore social aspects of organ donation in Slovenia. The project objective is to create guidelines and recommendations for developing a programme aimed at changing behaviours related to organ and tissue donation (32,54,55).

7 Challenges of the Slovene donor programme

Preservation of life is the primary goal pursued by a physician who cares for a patient with devastating brain injury. Healthcare providers should consider every patient with severe brain injury and suspected brain death as a potential organ and tissue donor. Deceased donor management requires an active approach. Unfortunately, potential organ donors are often missed because of inadequate knowledge, legislative obstacles, inadequate support by responsible institutions, work overload or ethical dilemmas (56,57).

Once the decision has been made to withdraw active treatment because of the patient's unresponsiveness to therapy, the provision of palliative and end-of-life care becomes the primary concern of the physician in charge of the patient management. Also at this stage of care, potential organ donation should be considered, particularly in those patients who had opted for organ donation after death.

The Spanish Society of Intensive Care and Coronary Units (SEMICYUC), the American College of Critical Care Medicine and the Council of Europe have developed the code of ethics and recommendations for health professionals providing end-of-life care in ICUs: patients receiving palliative or end-of-life care are presented as potential deceased organ donors and the treatment guidelines consider possible organ and tissue donation after death (58-60). All codes of ethics and treatment guidelines issued to date have emphasised two elements of end-of-life care: the importance of protecting the rights of the patient who had expressed willingness to donate organ when alive and the impor-

tance of offering assistance to the family in making decision for organ donation. Deciding on further management of these patients, a comprehensive approach that protects the patients' interests should be considered and, in addition to addressing relevant medical and clinical issues, should be based on the principle of the patient's autonomy (56-62). In Slovenia, an initiative was given to include the issue of potential organ and tissue donation after death in the code of ethics (63). Currently, the initiative is being considered by the professionals involved in the formulation of new ethical guidelines for end-of-life care in ICUs. Adoption of these code's novelties is a prerequisite for the implementation of the initiative.

8 Conclusion

Slovenia Transplant carries out its programme in collaboration with several institutions and organisations at the hospital, national and international

levels. The success of the donor programme is dependent on the correct and effective execution and coordination of all stages of the donor process and on continuous education and training of healthcare professionals involved in transplantation activities.

Despite turbulent times in the Slovene healthcare system, we witness a decrease in the number of family refusals to donation, a steady increase in the number of persons registering as donors during their lifetime and a rising number of deceased organ donors. These developments indicate a high level of public trust in the national organ donor system and the Slovenia Transplant.

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