
CRITICAL FACTORS FOR SUCCESS IN DECEASED DONATION: AN INTERNATIONAL STUDY

Survey results and final report of project TO077 on behalf of
the Council of Europe European Committee (Partial
Agreement) on Organ Transplantation (CD-P-TO)

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Background/aim

Project TO077 of the European Committee (Partial Agreement) on Organ Transplantation (CD-P-TO) was initiated with the aim of gaining insight into the determinants that may influence the donation rates in the Council of Europe member states, and the success factors for increasing organ availability. An online survey was conceived of and conducted by the project TO077 working group.¹

Methods

The online survey "Critical factors for success in deceased donation: an international study" was aimed at collecting information about measures implemented by the Council of Europe member states to promote deceased organ donation during the years 2002 to 2017. CD-P-TO members were invited by e-mail to take the online survey; participation was open from June to December 2018.

Results

The following countries participated in the survey: Belgium, Czech Republic, Estonia, Italy, Latvia, Lithuania, Republic of Moldova, Netherlands, Poland, Slovakia, Slovenia, Spain, Switzerland, United Kingdom. The participation rate was 39% (14/36).

Overview on survey topics

Domain 1: "Detection and referral of possible donors"; areas in Domain 1 include:

- Resources (e.g. finances, staff, infrastructure)
- Organisation (e.g. structures, guidelines)
- Hospital staff awareness, training, commitment, accountability

Domain 2: "Extension of donor pool"; areas in Domain 2 include:

- Donor viability (e.g. extended criteria donors, technical measures)
- Donation after cardiocirculatory death

Domain 3: "Obtaining consent"; areas in Domain 3 include:

- Patient/family refusal (e.g. training of staff, timing of approach, consent policy/modality, incentives)
- Public awareness for organ donation (e.g. public campaigns, media coverage)

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QUESTION: Please indicate the domains and areas in which measures have been implemented.

Table 1: Overview of domain answers by country

	Belgium	Czech Republic	Estonia	Italy	Latvia	Lithuania	Republic of Moldova	Netherlands	Poland	Slovakia	Slovenia	Spain	Switzerland	United Kingdom
Domain 1: measures implemented														
Resources														
Organisation														
Staff														
Other														
Reason for no measures implemented														
Legal restrictions														
Other reasons														
Domain 2: measures implemented														
Donor viability														
DCD														
Other														
Reason for no measures implemented														
Lack of resources														
Legal restrictions														
Other reasons														
Domain 3: measures implemented														
Patient/family refusal														
Public awareness														
Other														
Reason for no measures implemented														
Other reasons														

Red squares: no measures implemented, green squares: measures implemented.

Detailed answers

Domain 1: "Detection and referral of possible donors"

QUESTION: Please provide a short description of measures implemented in area "resources".

Table 2: Measures implemented in area "resources"

Belgium	Financial support for hospitals (part-time nurse): registration of each death in intensive care (donor detection). Financial support for training on family approach.
Czech Republic	Health insurance pays hospitals for donor identification. Health insurance pays for reimbursement of lost income of living donors. Contribution to funeral costs of deceased donors.
Italy	Since 2014 CNT has managed the national allocation platform with 15 new people (nurses and medical doctors) working on-call 24/7. The national allocation office is currently situated in a separate building within the national institute of health, where it is possible for working staff to stay during the night shift.
Lithuania	Since 1999 there have been national Compulsory Health Insurance Fund payments for identification and preparation of donors – for donor hospitals and laboratories. In 2008 payments were split up by stages. 2,100 EUR 2018 amount of EUR -The amount insignificant rises up (now 2,100 EUR for 1 donor). AUTHORITY: NTB, Ministry of Health. TARGET - national, mandatory
Republic of Moldova	AIM: Establishment of the Transplant Agency with the major goal of efficiently implementing state policy in the field of the transplantation of human organs, tissues and cells. AUTHORITY: Initiated/implemented by Government/Ministry of Health. TARGET: national level. CHARACTERISTIC: mandatory. YEAR: 2010. AIM: Financing of the donation and transplantation of human organ activities by establishment of the financial mechanism to pay a specific fee for pre-surgical maintenance therapy of potential brain-dead organ donors in ICUs. Aimed at reimbursement and motivating the staff involved. AUTHORITY: Initiated/implemented by Transplant Agency/Ministry of Health. TARGET: national level. CHARACTERISTIC: mandatory. YEAR: 2014.
Netherlands	AIM: Since 2002, donation coordinators have been appointed in Dutch hospitals to increase donor awareness and implement and evaluate donation policy, with the aim of increasing the number of post mortem donors. AUTHORITY: Dutch Transplant Foundation, with financial support of the Ministry of Health. TARGET: local level. CHARACTERISTIC: supportive. YEAR: ongoing
Poland	1. National Program for The Development of Transplantation Medicine with yearly budget of about 10 million Euro to support donation and transplant departments, education and public campaigns in the areas of deceased and live donation. AUTHORITY: Parliament, Government, Ministry of Health, Poltransplant. CHARACTERISTIC: supportive. TARGET: national level. YEAR: since 2011. REFERENCES: The Council of Ministers resolution of 12 October 2010 on establishment of longstanding program for the years 2011-2020 called National Program for the Development of Transplantation Medicine. Resolution No 164, 2010. http://www.poltransplant.org.pl/uchwala_rm_1642010.html . Accessed 21.09.2015
Slovakia	Finances are allocated to hospitals which identify donors.
Slovenia	At Slovenija transplant we are constantly looking for additional finances to supplement the regular governmental budget. We have succeeded in joining other countries to be a partner in many EU projects. The outcomes of the projects have brought us more knowledge, new results, strategies and material to educate different target groups about donation and transplantation. Considering these aspects, we have significantly improved the financial part during the last 15 years. Furthermore, we have made important improvements to human resources. Namely, in 2002, when Slovenija transplant was established and started to work independently, we succeed in employing four times more full-time staff and 50% more contractors. The selection criteria for new experts have changed in line with new needs and have also been constantly improved. The management team of Slovenija transplant has been in charge of proposing different new ideas, organisational changes, holding interviews with new expert candidates, designing the project proposals, searching for new partners for the projects, implementing the outcomes and results, and checking the current situation using SWOT analysis. Based on the results, the management team has prepared an annual educational plan for the national donation program, implementing it by inviting the best presenters and tutors, and working constantly with the media in the most open way concerning credibility of information and clinical results. The Ministry of Health requests the annual report every year to confirm the annual plan for the next year. The members of the supervisory board are nominated every four years and control all aspects of Slovenija transplant, including indicators of effectivity and quality in the donor program and whether the aims of the plan have been fulfilled.
Switzerland	National Action Plan (action field "structures and resources in hospitals"): Allocation of earmarked funds to healthcare professionals charged with tasks related to organ donation (local organ and tissue donation coordinators). AIM: Remuneration of defined percentages of coordinators' working time (with enhanced accountability concerning the specific tasks of the coordinators). AUTHORITY: The National Action Plan was initiated by the Federal Office of Public Health. Financing for the measures in action field "structures and resources in hospitals" is provided by the cantons. The measures were implemented by

	Swisstransplant/Comité National du Don d'Organes. TARGET: National level. CHARACTERISTIC: Mandatory YEAR: The National Action Plan started in 2013.
United Kingdom	AIM Infrastructure - The overarching UK infrastructure changes that laid the foundation for the UK's improvements in deceased donation from 2008 – present were the publication and then implementation of the 14 Organ Donation Taskforce Recommendations. https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/4245/organsfortransplants-theorgandonortaskforce1streport.pdf 14 Recommendations Recommendation 1 A UK-wide Organ Donation Organisation should be established. - merger with blood service to create NHS Blood and Transplant (NHSBT). Organ Donation and Transplantation Service had a budget of approximately £10 million per annum before 2008. Current budget approximately £74 million per annum. Recommendation 2 The establishment of the Organ Donation Organisation should be the responsibility of NHSBT. Recommendation 3 Urgent attention is required to resolve outstanding legal, ethical and professional issues in order to ensure that all clinicians are supported and are able to work within a clear and unambiguous framework of good practice. Additionally, an independent UK-wide Donation Ethics Group should be established. - multiple publications of ethics, law and professional practice. The UK Donation Ethics Committee ran from 2009-2016. Recommendation 4 All parts of the NHS must embrace organ donation as a usual, not an unusual event. Local policies, constructed around national guidelines, should be put in place. Discussions about donation should be part of all end-of-life care when appropriate. Each Trust should have an identified clinical donation champion and a Trust donation committee to help achieve this. Recommendation 5 Minimum notification criteria for potential organ donors should be introduced on a UK-wide basis. These criteria should be reviewed after 12 months in light of evidence of their effect, and the comparative impact of more detailed criteria should also be assessed. Recommendation 6 Donation activity in all Trusts should be monitored. Rates of potential donor identification, referral, approach to the family and consent to donation should be reported. The Trust donation committee should report to the Trust Board through the clinical governance process and the medical director, and the reports should be part of the assessment of Trusts through the relevant healthcare regulator. Benchmark data from other Trusts should be made available for comparison. Recommendation 7 Brain stem death testing should be carried out in all patients where brain stem death is a likely diagnosis, even if organ donation is an unlikely outcome. Recommendation 8 Financial disincentives to Trusts facilitating donation should be removed through the development and introduction of appropriate reimbursement. Recommendation 9 The current network of donor transplant coordinators should be expanded and strengthened through central employment by a UK-wide Organ Donation Organisation. Additional co-ordinators, embedded within critical care areas, should be employed to ensure a comprehensive, highly skilled, specialised and robust service. There should be a close and defined collaboration between DTCs, clinical staff and Trust donation champions. Electronic on-line donor registration and organ offering systems should be developed. Recommendation 10 A UK-wide network of dedicated organ retrieval teams should be established to ensure timely, high-quality organ removal from all heart-beating and non-heart-beating donors. The Organ Donation Organisation should be responsible for commissioning the retrieval teams and for audit and performance management. Recommendation 11 All clinical staff likely to be involved in the treatment of potential organ donors should receive mandatory training in the principles of donation. There should also be regular update training. Recommendation 12 Appropriate ways should be identified of personally and publicly recognising individual organ donors, where desired. These approaches may include national memorials, local initiatives and personal follow-up to donor

	families. Recommendation 13 There is an urgent requirement to identify and implement the most effective methods through which organ donation and the "gift of life" can be promoted to the general public, and specifically to the BME population. Research should be commissioned through Department of Health research and development funding. Recommendation 14 The Department of Health and the Ministry of Justice should develop formal guidelines for coroners concerning organ donation. AUTHORITY: All four UK departments of health. TARGET: United Kingdom. CHARACTERISTIC: Supportive. YEAR: 2008 AIM Staff - The creation throughout the United Kingdom of approximately 250 full-time equivalent specialist nurses for organ donation (SN-OD) embedded in intensive care units and approximately 250 clinical leads for organ donation (senior doctors, usually intensive care physicians) in every acute hospital with donation potential on four hours per week to take a leadership and championing role. Referral goal A patient for whom neurological death is suspected or for whom imminent death is anticipated, i.e. receiving assisted ventilation, a clinical decision to withdraw treatment has been made and death is anticipated within four hours, should be referred to a Specialist Nurse for Organ Donation. Between 1st April 2017 and 31st March 2018 the donation after brainstem death (DBD) referral rate was 99% and the donation after circulatory death (DCD) referral rate was 89%. AUTHORITY: NHS Blood and Transplant. TARGET: United Kingdom. CHARACTERISTIC: Mandatory (having a specialist nurse or clinical lead is mandatory). YEAR: 2009
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QUESTION: Please provide a short description of measures implemented in area "organisation".

Table 3: Measures implemented in area "organisation"

Belgium	Each hospital (circa 90) has a medical and nurse donor coordinator.
Czech Republic	Introduction of transplant coordinators in some hospitals.
Italy	Update of national guidelines on DCD, national crossover programme.
Lithuania	The procedure for preparation of the Donor was approved by the legal act of the Minister of Health in 2008; this is mandatory for the donor hospital. In 2015 NTB issued a methodological tool for physicians and residents. Donor hospital reanimatologists helped in this area and a publication was distributed at national-level donor hospitals. The publication is intended to facilitate the process of donor preparation. AUTHORITY: NTB. CHARACTERISTIC: supportive. TARGET: information for donor hospitals
Republic of Moldova	AIM: Development of the transplant system with the aim of ensuring equal access for patients to transplantation services at the national level by authorising the 16 medical-sanitary institutions to conduct activities in the field of donation and transplantation, creating a tissue bank, implementing the automated information system "TRANSPLANT" AIS for monitoring of activities concerning human organ, tissue and cell procurement and transplantation, creating an HLA typing laboratory. AUTHORITY: Initiated/implemented by the Transplant Agency/Ministry of Health. TARGET: national level. CHARACTERISTIC: supportive/mandatory. YEAR: 2011-2013. AIM: Guideline on the organisation and conduct of the procurement and transplant of human organs, tissues and cells. Aimed at quality assurance and safety of procurement and transplant procedures. AUTHORITY: Initiated/implemented by the Transplant Agency/Ministry of Health. TARGET: national level. CHARACTERISTIC: mandatory. YEAR: 2017
Netherlands	AIM: in 2008 the Masterplan for Organ Donation was implemented with the aim of improving the number of donors. Dutch hospitals were divided into clusters. A cluster contains one large hospital (high number of organ donors) where a "donation intensivist" has been appointed to support the smaller hospitals within the cluster with their donation activities. AUTHORITY: Dutch Transplant Foundation, with financial support of the Ministry of Health. TARGET: local level. CHARACTERISTIC: supportive. Year: ongoing.

Poland	1. Setting up and running the national system of donor hospital transplant coordinators in about 200 hospitals with potential for donation performed and financed by Poltransplant. AUTHORITY: Poltransplant, hospital directors. CHARACTERISTIC: supportive. TARGET: national level. YEAR: since 2010. REFERENCES: System of donor hospital transplant coordinators maintained and financed by national transplant organisation improves donation rates, but is effective in only half of hospitals. Transplant Proc. 2014;46(8):2501-4 2. Hospital stratification according to potential for deceased donation. Criteria for these stratifications are as follows: ICU (yes/no), neurosurgery (y/n), stroke department (y/n), multispecialty hospitals vs small county hospitals. AUTHORITY: Poltransplant. TARGET: national level. YEAR since 2016. REFERENCES: Hospital Profiling And Hospital Stratification System As A Step For Assessment The Potential Of Organ Donation From Deceased Donors Research article Transplantation Proceedings, In press, accepted manuscript, Available online 28 March 2018 3. Hospital Quality Improvement Programs (web-netted, maintained by Poltransplant - koordynator.net) in hospitals with donation for monitoring and internal auditing of donation pathways. AUTHORITY: Poltransplant, hospitals. TARGET: national level. CHARACTERISTIC: supportive. YEAR: since 2014. REFERENCES: System of Monitoring Potential Deceased Organ Donations in Over 200 Hospitals in Poland Using a Web Tool: Implementation and Structure. Transplant Proc. 2016; 48(8): 1381-6
Slovakia	Donor program is supported by the Ministry of Health
Slovenia	A national network was established 25 years ago, but has been improved constantly. The Slovenija transplant management team has led all changes in procurement hospitals related to the organisational scheme and financial reimbursement. The Slovenija transplant team has prepared guidelines with algorithms for the national coordination office and for all procurement (so-called donor) hospitals. The cooperation with all donor hospitals is based on requirements defined by law and in bilateral agreement, and renewed when needed.
Spain	Different Guidelines developed with the Spanish Society of Emergency Care and the Spanish Society of Intensive Care for the early identification and referral of possible organ donors from within and outside of the ICU -- including the application of intensive care to facilitate organ donation (ICOD).
Switzerland	National Action Plan (action field "processes and quality management") AIM: Establishment and implementation of nationally standardised guidelines and processes. AUTHORITY: The measures in action field "processes and quality management" were implemented by Swisstransplant/Comité National du Don d'Organes. TARGET: National level. CHARACTERISTIC: Mandatory. YEAR: The National Action Plan started in 2013.
United Kingdom	AIM Guideline - The publication of Timely Identification and Referral of Potential Organ Donors: A Strategy for Implementation of Best Practice. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1337/timely-identification-and-referral-of-potential-organ-donors-nhsbt.pdf Performance metrics are shared biannually with hospitals and via the organ donation regional collaboratives which were established in 2011. AUTHORITY: NHS Blood and Transplant. TARGET: United Kingdom. CHARACTERISTIC: Supportive. YEAR: 2012

QUESTION: Please provide a short description of measures implemented in area "hospital staff".

Table 4: Measures implemented in area "hospital staff"

Belgium	Local and national protocols + organisation of training on donation and family support
Czech Republic	Education and training of health professionals
Italy	Annual training courses are planned twice a year for transplant coordinators (Italian TPM). CNT also organises, in cooperation with Padua transplant centre and Veneto regional centre, the DONOR training course for transplant surgeons. In 2015, in the framework of ACCORD JA, a course was organised dedicated to specific aspects of donation-coordination and communication in critical situations. In addition to this there are also other courses organised regionally.
Lithuania	The 2016 legal act signed by the Minister of Health provides for the concept of a donation coordinator. Some hospitals now have a donation coordinator or are encouraged with a financial supplement for the donation

	process. There is smooth communication between the National Coordinator and the Donor Hospital Coordinator. Kaunas University Clinics, a Lithuanian University of Health Sciences Hospital - one of the donor hospitals - is conducting a thorough training course on organ donation and transplantation. At the national level, everyone who wants to can take part. Information is then disseminated. TPM Courses Listen to Lithuanian Professionals: Face-to-face – 24; Online – 21.
Republic of Moldova	AIM: Online education program for healthcare professionals involved in the organ donation process. Aimed at improving knowledge about organ donation, harmonising the procedure and assuring high quality standards. AUTHORITY: Initiated/implemented by the Transplant Agency, Ministry of Health/TWINNING Project "Strengthening the Transplant Agency of the Republic of Moldova and support in legal approximation in the area of quality and safety of substances of human origin". TARGET: national level.
Netherlands	AIM: To improve the consent rate for donation, all intensivists completed the "Communication about Donation" training. This was part of the Masterplan for Organ Donation. In addition, all family approaches for donation were evaluated, to get insight into the bottlenecks. AUTHORITY: Dutch Transplant Foundation, with financial support of the Ministry of Health. TARGET: local level. CHARACTERISTIC: supportive. Year: 2008-2016.
Poland	1. Implementation of ETPOD training in 80 hospitals to improve knowledge among hospital staff and to support the position of hospital transplant coordinators. AUTHORITY: Poltransplant, Polish Union for Transplantation Medicine (NGO). TARGET: national level. CHARACTERISTIC: supportive. YEAR: since 2010. REFERENCES: Implementation and Sustainability of European Training Program on Organ Donation in Poland: Results and the Impact on Donation Indicators. Transplant Proc. 2016; 48(8): 2429-33 2. Continuous training (every year) for transplant coordinators affiliated with Poltransplant to improve knowledge and practices. AUTHORITY: Poltransplant. TARGET: national level. CHARACTERISTIC: mandatory. YEAR: before 2002. REFERENCES: XXIX Poltransplant Conference for Transplant Coordinators. Warsaw 2014 November 13-14. http://www.poltransplant.org.pl/szkolenie_koordinatorow_2014.html. Accessed 21.09.2015. 3. Organ Donation Hospital Quality System. Preparing "know how" on patterns from ODEQUS program to organise and document donation processes in hospitals. AUTHORITY: Poltransplant, hospitals. TARGET: donor hospitals. CHARACTERISTIC: supportive. YEAR: since 2015. REFERENCES: Effective Application of a Quality System in the Donation Process at Hospital Level. Transplant Proc. 2016; 48(8): 1387-9
Slovakia	There are training sessions for hospital staff involved in the donor program.
Slovenia	Based on regular checking of the effectivity of the hospital donor program, we have regular meetings with hospital management teams and hospital transplant coordinators. To check the effectiveness and quality of the donor program, we use a Quality assurance program installed in all donor hospitals.
Spain	Training activities on early identification and referral and ICOD organised and targeted at all professionals managing patients who could be considered possible organ donors.
Switzerland	National Action Plan (action field "training of medical staff"): Online education program for healthcare professionals involved in the organ donation process. AIM: Aimed at improving knowledge about organ donation, harmonising the procedure and assuring high quality standards. AUTHORITY: The online education program was implemented by Swisstransplant/Comité National du Don d'Organes. TARGET: National level. CHARACTERISTIC: Supportive/mandatory (depending on function). YEAR: The National Action Plan started in 2013.
United Kingdom	AIM The UK has introduced a number of hospital staff education initiatives. Local hospital – education by clinical leads and specialist nurses for organ donation. The UK has embraced deceased donation simulation training. 6 hospitals have introduced local simulation courses. Regional Courses – the Northern Region of England runs annual clinician consent training days. Bristol and Sheffield run paediatric simulation courses. National Courses – the two-day deceased donation course for intensive care trainees commenced in 2013 and ran five times over the last year (Day 1 lectures, Day 2 simulation). The intention is to run six times per year so that the entire graduating cohort of UK intensive care medicine trainees can be catered for. AUTHORITY: NHS Blood and Transplant (NHSBT) and local hospital organ donation committees. TARGET: United Kingdom. CHARACTERISTIC: Supportive. YEAR: 2011.

QUESTION: Please provide a short description of measures implemented in area "other".

Table 5: Measures implemented in area "other"

Belgium	Awareness campaigns nationally, locally, in the press...
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Italy	Since 2013 it has been possible to express positive or negative consent to organ donation during renewal or first issue of the ID card. All the information collected is stored in the National IT registry.
Poland	1. The model for Postgraduate Studies for Transplant Coordinators is well recognised in Poland as well as abroad. AIM: To educate new donor and transplant coordinators. Organised at the Medical University of Warsaw. AUTHORITY: Medical University of Warsaw, Poltransplant, Ministry of Health. TARGET: national level. CHARACTERISTIC: supportive. YEAR: since 2007. REFERENCES: The Model of Postgraduate Studies for Transplant Coordinators in Poland. 500 Graduates in the Years 2007-2015. Transplant Proc. 2016; 48(8): 1370-3.
Slovenia	As was already mentioned, the Slovenija transplant management team work constantly with the Ministry of Health and other important experts, such as lawyers, social science experts, religious leaders, media, IT experts, philosophers and anthropologists, to present medical aspects connected to altruistic donation and improve trust among the general public and experts coming from other professional areas. Interdisciplinary work has brought many advantages, which has been shown with the results in the donor program and the respect given to the donation and transplantation field of medicine.
Spain	1. Extended evaluation of the deceased donation pathway starting from all patients dead as a result of a devastating brain injury in Spanish hospitals performed with the ACCORD-Spain project (Domínguez-Gil B, et al. End-of-life practices in patients with devastating brain injury in Spain: implications for organ donation. Med Intensiva. 2017 Apr;41(3):162-173); 2. Plan, Do, Study, Act cycles organised with more than 100 hospitals throughout the country for donor coordination teams to implement small interventions that can facilitate the early identification and referral of possible organ donors within their centres; 3. Extension of the Spanish Quality Assurance Programme in Organ Donation to capture donation opportunities outside of the ICU currently being piloted.
Switzerland	Swiss Monitoring of Potential Organ Donors (SwissPOD). AIM: SwissPOD was initiated with the aim of providing detailed information on the detection and referral of potential organ donors by Swiss intensive care units and accident and emergency departments, and to reveal the causes of the overall low donation rate in Switzerland. AUTHORITY: Initiated by the Federal Office of Public Health and the Swiss university hospitals/transplant centres; implemented by Swisstransplant/Comité National du Don d'Organes. TARGET: national level. CHARACTERISTIC: mandatory. YEAR: 2011 (since 2012, SwissPOD has been used as a quality assurance program for the monitoring of the donation process in hospitals).

QUESTION: Please provide at least one reason why no measures have been implemented to improve the detection and referral of possible donors.

Table 6: Reasons why no measures have been implemented

	Legal restrictions	Other reasons
Latvia	National TX coordination service is a hospital structure that has no influence over other hospitals.	

Domain 2: "Extension of donor pool"

QUESTION: Please provide a short description of measures implemented in area "donor viability".

Table 7: Measures implemented in area "donor viability"

Belgium	Older donors, virology positive donors, using a perfusion machine for kidneys, starting to use a perfusion machine for liver.
Czech Republic	Introduction of extended criteria for all organs. Use of perfusion machine for kidney transplant.
Italy	The use of perfusion machines has been implemented in some regions
Latvia	The aim was to increase the number of available organs and to reduce the number of not used donors. It was implemented in 2002 by the Latvian Transplantation centre, at national level. The main focus was on the use of elderly donors.
Lithuania	In 2008, absolute contraindications for organ donation were established in the order of the Minister of Health. However, doctors are increasingly starting to use expanded criteria donor organs, for example, kidneys and livers from older donors are transplanted. Each time the donor organs are evaluated taking into account the recipient's condition. We always weigh the benefits and risks to the recipient. Unused donor organs are offered abroad. Successful cooperation with Latvia, FOEDUS platform, Eurotransplant. One of the LT transplant centres has had a kidney perfusion machine since 2017 and uses it successfully.
Republic of Moldova	AIM: Improving the critical care facilities needed for the appropriate haemodynamic management of the critically ill patient/potential brain-death donor. Monitoring of these critically ill patients/potential brain death donors at the level of current UCI International standards. AUTHORITY: Initiated/implemented by Transplant Agency/Ministry of Health. TARGET: national level. CHARACTERISTIC: mandatory. YEAR: 2014.
Netherlands	AIM: increasing the pool of potential organ donors using extended criteria donors. The age criteria for liver and kidney donation have been relaxed. AUTHORITY: implemented by the Dutch Transplant Foundation, based on the advice of the national organ committees. TARGET: hospital level. CHARACTERISTIC: mandatory. YEAR: 2010. AIM: improving the quality of post mortem organs by ex vivo machine perfusion of all donor kidneys. AUTHORITY: implemented by the Dutch Transplant Foundation, based on the advice of the national kidney committee. TARGET: hospital level. CHARACTERISTIC: mandatory. YEAR: 2016 TARGET: hospital level. CHARACTERISTIC: optional. YEAR: 2017 AIM: improving use of extended criteria non-renal organs (lungs and livers) by using machines to check and improve organ function. AUTHORITY: implemented by the Dutch Transplant Foundation, based on the advice of the national lung and liver committees. TARGET: transplant centre level. CHARACTERISTIC: supportive. YEAR: 2016 TARGET: hospital level. CHARACTERISTIC: optional. YEAR: lungs: 2013, liver: 2017.
Poland	1. Organ utilisation from anti-HBcore positive donors to extend the donor pool (the percentage of such donors is 14% of all referred) and from anti-HCV positive donors (2% of the total number of referred donors). AUTHORITY: Poltransplant, transplant centres. CHARACTERISTIC: optional. YEAR: since 2007. REFERENCES: Viral Hepatitis B and C markers In the Population of Deceased Donors In Poland. Transplant Proc 2007; 39: 2695-7.
Slovenia	Slovenija transplant experts succeeded in presenting the idea that age is not important for donation. Furthermore, we succeeded in disseminating the idea that the final decision on donation should be confirmed by the Slovenija transplant expert team and not intensive care doctors, because they interrupted the donation procedures too many times due to contraindications which are more relative than absolute. We invited them to call us and based on the interdisciplinary medical consultation we either continue with the donation procedure or stop.
Spain	1. The use of expanded and non-standard risk donors (NSRD) is current practice in Spain. The use of organs from NSRD has been based on national consensus documents, recently being updated on the basis of the Council of Europe Guides and internal work performed in Spain by ONT with the relevant professional societies. 2. A prospective assessment of outcomes of recipients of organs from NSRD is undertaken with the whole Spanish network, organised by ONT, with periodical reports produced for the network and supporting decision-making in this particular field; 3. ONT has physicians on call for a second opinion related to the risk assessment of donors and organs to be used for transplantation.
Switzerland	Perfusion machines for kidneys (since 2015), lungs (introduction depending on transplant centre, 2016 or earlier), livers (introduction depending on transplant centre, 2018 or earlier).

	Extended criteria donors: Since 2017, organs from HCV-positive donors have been included in organ allocation.
United Kingdom	AIM Technical measures. In an increasing number of UK organ donations, retrieval and transplant surgeons utilise in situ (e.g. in liver and heart DCD) and ex-situ (particularly hearts, lungs and kidneys) organ preservation techniques. AUTHORITY: NHS Blood and Transplant (NHSBT), National Organ Retrieval Service and individual UK Transplant Centres. TARGET: United Kingdom. CHARACTERISTIC: Supportive. YEAR: 2012 (variable start) AIM Publication and commencement of implementation of the Taking Organ Utilisation to 2020. This strategy sets out the improvements that could be made across the donation and transplantation pathway to ensure that as many organs as possible are safely transplanted. It focuses on two key areas – organ acceptance and organ utilisation. https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/taking-organ-utilisation-to-2020/ AUTHORITY: NHS Blood and Transplant (NHSBT). TARGET: United Kingdom. CHARACTERISTIC: Supportive. YEAR: 2017

QUESTION: Please provide a short description of measures implemented in area "donation after cardiocirculatory death".

Table 8: Measures implemented in area "donation after cardiocirculatory death"

Belgium	DCD category 2,3 and 4
Czech Republic	All centres have started a DCD program.
Italy	Some transplant centres have started activity from DCD Uncontrolled II, Controlled III, in ECMO
Latvia	This type of donor has been used from the beginning of transplantation in our country (since 1973), only for kidney donation. This type of donor has been used in 99% of hospitals near the transplantation centre.
Lithuania	In 2016, the Law on Emergency Situations was revised at the national level. Work was done by working group members, who were approved by the Minister of Health. This was a legitimate opportunity to prepare donors after cardiac death. Since 2016 Procedures have been developed for the preparation of cardiac donors (Health Minister legal act), but the signature of the Minister of Health has not yet been approved, because the calculation of the cost of preparation of such donors is being carried out. In 2016, 2 NHS donors were already prepared according to donor hospital procedures.
Netherlands	AIM: extending the number of organs from a DCD donor; donation of livers and lungs. AUTHORITY: implemented by the Dutch Transplant Foundation, based on the advice of the national liver and lung committee. TARGET: hospital level. CHARACTERISTIC: mandatory. YEAR: 2005
Poland	1. Reintroduction of DCD donation (uncontrolled). AIM: To increase donor pool. AUTHORITY: transplant centres. CHARACTERISTIC: optional. YEAR: since 2015. REFERENCES: Assessment of Donation Potential After Circulatory Death as the First Step in Implementing and Running a Hospital Program of Organ Procurement. Transplant Proc. 2016; 48(8): 1399-401
Slovenia	We have not implemented the DCD program in Slovenia yet.
Spain	Uncontrolled donation after circulatory death (uDCD) has been a reality in Spain since the 1980s. Controlled DCD (cDCD) was first piloted in 2009. In 2012, the Spanish regulatory framework (national consensus document and recommendations, as well as legislation) were adopted that embraced the practice of both uDCD and cDCD. This has been supported by training, professionals' recommendations, national data collections to evaluate practices and results, and important institutional support.
Switzerland	AIM: Reintroduction of donation after cardiocirculatory death. After the coming into force of the National Transplantation Act in 2007 it was unclear if DCD was still lawful. A working group was created which clarified the issue together with the Federal Office of Public Health and the transplant centres. AUTHORITY: Initiated/coordinated by Swisstransplant, implemented by the management of the individual transplant centres. TARGET: Hospital level. CHARACTERISTIC: Optional. YEAR: 2011 (restart of DCD program).
United Kingdom	AIM Multiple supportive ethical, legal and professional publications allowed UK controlled donation after circulatory death to grow until it now represents approximately 40% of deceased organ donors. A Code of Practice for the Diagnosis and Confirmation of Death from the Academy of the Medical Royal Colleges (2008, which covered the diagnosis of death after cardiorespiratory arrest). https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/1359/donation-after-circulatory-death-code-of-

	practice-for-the-diagnosis-and-confirmation-of-death.pdf Legal Guidance on Donation after Circulatory Death in England, Scotland, Wales and Northern Ireland. From 2009. http://webarchive.nationalarchives.gov.uk/20130124052416/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_109864.pdf Consensus statement on Donation after Circulatory Death from the British Transplantation Society and Intensive Care Society (2010) https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1360/donation-after-circulatory-death-dcd_consensus_2010.pdf UK Donation Ethics Committee: An ethical framework for controlled donation after circulatory death (2011) http://www.aomrc.org.uk/wp-content/uploads/2016/04/Ethical_framework_donation_circulatory_death_1211-3.pdf AUTHORITY: Multiple. TARGET: United Kingdom. CHARACTERISTIC: Supportive. YEAR: 2008
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QUESTION: Please provide a short description of measures implemented in area "other".

Table 9: Measures implemented in area "donation after cardiocirculatory death"

Belgium	Euthanasia donors, Crossover donation
Italy	Further development of the National crossover program starting with Samaritan donors. In 2018 Padua transplant centre started the first kidney exchange chain from DBD. At EU level, a crossover programme in the framework of the SAT agreement with the Spanish and Portuguese transplant organisations. The first KEP was performed in July 2018 between a Spanish and Italian couple and further match runs are planned for the future.
Slovenia	As mentioned above the most important progress in the donation chain has been done in the registration and evaluation process and very open cooperation between ICU specialists and coordinators for donation activities mentors working at Slovenija transplant.

QUESTION: Please provide at least one reason why no measures have been implemented to extend the donor pool.

Table 10: Reasons why no measures have been implemented

	Lack of resources	Legal restrictions	Other reasons
Slovakia		There is no support in law in Slovakia for DCD.	

Domain 3: "Obtaining consent"

QUESTION: Please provide a short description of measures implemented in area "patient/family refusal".

Table 11: Measures implemented in area "patient/family refusal"

Belgium	Training 4 times a year: family support for intensive care doctors and nurses.
Czech Republic	Regular staff training, organised by individual centres.
Italy	A national campaign aimed at encouraging the population to talk about organ donation in the family was launched in 2017 and is presently ongoing; "TVD" and "Salvo e Gaia" aimed at primary and secondary schools.
Latvia	The aim was to improve ICU personnel skills in approaching donor families, implemented in 2000 by Latvian Transplantation Centre - annual meetings and seminars for ICU staff.
Lithuania	In Lithuania, there is an informed consent model: if a person did not express a will to donate while alive, his relatives decide whether a dead person will become a donor. A donor-trained reanimatologist talks about organ donation with the potential donor family after a brain death. The written consent form is approved by the Minister of Health. Donor family refusals varied from 25 % in 2008 to 43 % in 2014. The Donor Card was approved by the Minister of Health in 2000. Since 2014, it can be signed online via electronic government gateways. About 28 000 people have Donor Cards in Lithuania.
Republic of Moldova	AIM: Training of Transplant Coordinators' Trainers. Aimed at the subsequent training of future hospital transplant coordinators in each respective authorised hospital. AUTHORITY: Initiated/implemented by Transplant Agency/TAIEX expert mission. TARGET: national level. CHARACTERISTIC: mandatory. YEAR: 2012. AIM: Strengthening of the staff capacity. Implemented by face-to-face training modules organised on family approach. AUTHORITY: Initiated/implemented by Transplant Agency, Ministry of Health/TWINNING Project "Strengthening the Transplant Agency of the Republic of Moldova and support in legal approximation in the area of quality and safety of substances of human origin". TARGET: national level. CHARACTERISTIC: mandatory. YEAR: 2015.
Netherlands	AIM: increasing the consent rate by developing training for health care professionals on "Communication about Donation". In addition, organising expert meetings for donation intensivists to exchange best practices. AUTHORITY: Initiated/implemented by the Dutch Transplant Foundation, with financial support of the Ministry of Health. TARGET: hospital level. CHARACTERISTIC: supportive. YEAR: 2007.
Poland	1. "Partnership for Transplantation". A new comprehensive program. The letter of intent to activate the donation program was signed by the local administration, the president of the local medical school, president of the Physician's Chamber, transplant centres, the Polish Union for Transplantation, and Poltransplant. The plan of action included training of in-hospital coordinators, visits to all regional hospitals in company of a representative of the hospital founding body, examination of the real donation pool and the need for participation in a donation program, training and education of the hospital staff in legal and organisational aspects of donation, brain death recognition and various aspects of donor care. In addition, the program included communication skills workshops for intensive care unit physicians (with participation of 2 actors, an experienced anaesthesiologist and a psychologist), lectures for high school and university students and for hospital chaplains as well as alumni of higher seminaries. AUTHORITY: Polish Union for Transplantation Medicine, Poltransplant, Medical Universities, Physicians' Chambers. TARGET: national level. YEAR: since 2010. REFERENCES: Partnership for Transplantation: A New Initiative to Increase Deceased Organ Donation in Poland. Transplant Proc 2012 Sep 44, 2176-7
Slovenia	In Slovenia, we succeeded in lowering the refusal rate significantly from 33% to 15%. The most important reason for this significant achievement is constant work and education about family interviewing, working with the family after donation, giving them a thank you and a letter on how to go through the grieving period, organising workshops in combination with clinical psychologists and actors, having debriefing consultations with HCP. Important aspects for successful interviews are based on the recommendation that family interview should be performed by the most skilled experts in combination with ICU doctors.
Spain	1. Guidance provided on family approach in critical situations and in that of posing the option of organ donation; 2. Continuous training for all professionals directly or indirectly involved in the communication with families in critical situations and for donor coordinators (and other professionals) who actively participate in the family approach to pose the option of organ donation in different scenarios.
Switzerland	Online education program for healthcare professionals involved in the organ donation process. (See answer Domain 1, Measure "hospital staff"; National Action Plan, action field "training of medical staff").

United Kingdom	AIM As well as the above measures to increase donor detection and referral, NHSBT published Approaching the families of potential organ donors: best practice guidance, which also included an educational video. http://odt.nhs.uk/pdf/family_approach_best_practice_guide.pdf https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/consent-and-authorisation-the-family-approach/ AUTHORITY: NHS Blood and Transplant. TARGET: United Kingdom. CHARACTERISTIC: Supportive. YEAR: 2013
	AIM Wales introduced deemed consent on 1st December 2015. This is a soft opt-out. To accommodate this legislative change the UK Organ Donor Register was altered to allow an opt-out to be recorded. AUTHORITY: Welsh Assembly and NHSBT. TARGET: United Kingdom. CHARACTERISTIC: Mandatory. YEAR: 2015
	AIM Newly employed specialist nurses for organ donation (SN-ODs) undergo six months of supernumerary training before they are on the on-call rota and may be approaching families on their own. New SN-ODs train in cohorts (usually two-three cohorts per year) and have a number of education modules they must complete. The final module of training includes a three-day simulation course. AUTHORITY: NHS Blood and Transplant. TARGET: United Kingdom. CHARACTERISTIC: Supportive. YEAR: 2016
	AIM In four of the 12 organ donation regions in the UK some SN-ODs have taken on the role of specialist requestor. The intention is that these SN-ODs lead on family approaches for donation consent. It is hoped that by their increased training and exposure their consent rates will be better than a regular SN-OD. AUTHORITY: NHS Blood and Transplant. TARGET: United Kingdom. CHARACTERISTIC: Supportive. YEAR: 2016

QUESTION: Please provide a short description of measures implemented in area "public awareness".

Table 12: Measures implemented in area "public awareness"

Belgium	More than 200 presentations in hospitals, cities, schools, etc. by transplantation coordinators, patient associations and others.
Czech Republic	Public campaigns in regional media KST organised a national press conference (Valentine's Day)
Italy	CNT has coordinated one project (COORENOR-2010/2012) a Joint Action (FOEDUS-2014/2016) and is presently part of the EUDONORGAN tender which aimed, among other things, to increase public awareness in the country. National campaigns are organised to make children and older people aware of the topic of organ donation and transplantation. Several Italian celebrities have supported organ donation and transplantation during public campaigns promoted by regional coordination centres and by voluntary associations. In October 2014 Italy organised the European Organ Donation Day (EODD) in cooperation with the Council of Europe. The aims of EODD 2014 were to: reinforce public awareness of organ, tissue and cell donation; promote the recording of adults' wishes concerning organ and tissue donation; invite people to discuss organ donation with relatives and friends; underline that donation culture is cross-border. After the event, some numbers were collated: Number of hits recorded in the statistics of AIDO (National Donor Association) website www.aido.it the day after the event (148 301); Increased percentage of hits on the AIDO website recorded the day after the event (+ 25.02%); Number of declarations collected during the Day through the form distributed by AIDO (190); Completed forms for the declaration of will downloaded from the website AIDO October 13 (3 781). In one month AIDO will compare the number of forms downloaded from the website with those actually received and registered as organ donors. Other national campaigns such as "Diamo il meglio di Noi" (for organ, tissue and cell transplantation) and "Match it now" (bone marrow donation) are run every year.
Latvia	All Latvian transplantation centre personnel have been involved in work with mass-media (since 1973) with the aim of improving public and medical society awareness.

Lithuania	One of the functions of the Bureau is the formation of a positive attitude towards donation in the country; 2011 NTB after the restructuring of the Communications Division. Active work in the field of publicity of donation. NTB organises educational activities - in schools, institutions, educational articles in the national media, TV, radio. Celebration of the donation days every October, collaboration with patient organisations that unite people who are waiting for and expecting transplants. Publication of positive stories encourages the public to sign an agreement on donation after death - to receive a donor card. There are cases in which the relatives of the donor themselves propose donating organs to the doctor, without the doctors mentioning donation.
Republic of Moldova	AIM: Strengthening communication and information. Aimed at increasing public awareness followed by increasing donor rate. Implemented by publishing leaflets about basic concepts in Donation and Transplantation, posting short videos on the Agency website, FB and links on all healthcare websites, organisation of Organ Donation and Transplantation day, of the Communication Campaign. AUTHORITY: Initiated/implemented by Transplant Agency/Ministry of Health. TARGET: national level/regional. CHARACTERISTIC: supportive/mandatory. YEAR: yearly.
Netherlands	AIM: increasing knowledge of the Dutch population about donation with a yearly national "Donor week". Further online campaigns via social media. AUTHORITY: Initiated by the Dutch Transplant Foundation commissioned by the Dutch Ministry of health. Public campaigns on organ donation by Dutch Ministry of health. TARGET: national level, general public. CHARACTERISTIC: supportive. YEAR: each year, still ongoing.
Poland	1. Nationwide public campaign "Consent to Live" with several aims: dissemination in society of knowledge about transplantation medicine; building broad public support for the idea of organ, cell and tissue donation; to encourage public declarations of acceptance regarding organ donation; the conviction of relatives to follow the will of the deceased; building knowledge and public awareness on the subject of legal regulations and death; encouraging people to become potential donors of bone marrow. AUTHORITY: Ministry of Health. TARGET: national level. YEAR: 2015-2016. REFERENCES: Poltransplant Bulletin 2016(24): 131-5. http://poltransplant.pl/Download/Biuletyn_2016_www.pdf
Slovakia	Slovak transplant society is the organiser of the National 7 lives project.
Slovenia	Slovenija transplant management team and experts have given much attention to increasing public awareness during the last 15 years. Communication with the media remains one of the most important tasks related to public awareness. Our normal routine way of working is to be open and available for the mediawith the latest results; we ask them to send back the texts, interview reports and other publications to check that they contain accurate medical details. We have organised many PR conferences to present media results and new achievements. On request, we try to find recipients willing to present their stories to the general public, which is very interesting for the media. Every year Slovenija transplant organises the European organ donation day with medical information and sports events. Slovenija transplant invites, besides HCP, recipients, media and donor families to join in. EODD is a very good opportunity to make donation and transplantation more popular. For many years we have planted trees as a symbolic gesture of the way donation and transplantation could grow.
Spain	Specific management of the media, including annual meetings between journalists and donor/transplant coordinators.
Switzerland	Periodic public campaigns by the Federal Office of Public Health. AIM: The aim of the latest campaign (2016) was that people talk about organ donation and that they communicate their decisions to their relatives. AUTHORITY: The Swiss government (Federal Office of Public Health). TARGET: National level (general public). CHARACTERISTIC: TV, Internet, billboard and print ads. YEARS: 2009, 2011, 2013, 2016. AIM: Smartphone application (Echo112 – Medical ID) that serves as a digital donor card. AUTHORITY: Initiated by app developer, supported by Swisstransplant. TARGET: National level (general public). CHARACTERISTIC: Supportive (free download). YEAR: 2014. Since 2012, it has been possible to add one's organ donor status to the Facebook timeline.
United Kingdom	AIM The Human Tissue (Scotland) Act 2006 establishes a duty on Scottish Ministers to promote information and awareness about the donation for transplantation of parts of a human body. AUTHORITY: Scottish Government. TARGET: Scotland. CHARACTERISTIC: Mandatory. YEAR: 2006 AIM In partnership with NHSBT the posthumous Order of St John Award for Organ Donation is offered to all deceased organ donors and if so wished, accepted by their families either by post or at special local ceremonies. The Order of St John is an order of Chivalry of the British Crown, and the award is often presented to families by a Lord Lieutenant, Her Majesty the Queen's local representative. AUTHORITY: Order of St John and NHSBT. TARGET: Wales. CHARACTERISTIC: Supportive. YEAR: 2013 AIM

	The Welsh government carried out an extensive media campaign ahead of the commencement of deemed consent legislation. AUTHORITY: Welsh Government. TARGET: Wales. CHARACTERISTIC: Supportive. YEAR: 2015 AIM As part of the Taking Organ Donation to 2020 a comprehensive behaviour change initiative has been launched with government funding. https://www.nhsbt.nhs.uk/tot2020/the-strategy/ https://www.nhsbt.nhs.uk/tot2020/about-the-strategy/changing-behaviour/ AUTHORITY: NHS Blood and Transplant. TARGET: United Kingdom. CHARACTERISTIC: Supportive. YEAR: 2016
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QUESTION: Please provide a short description of measures implemented in area "other".

Table 13: Measures implemented in area "other"

Belgium	A federal donor truck has been visiting students in primary schools for 2 years. The population now has the opportunity to register themselves as donors in the town halls at any local or national political election.
Poland	1. Guidelines for donor coordinators: "Organ and Tissue Procurement From Non-residents Deceased in Poland: Guidelines for Transplant Coordinators". New approach in response to increasing global mobility. AUTHORITY: Poltransplant. TARGET: worldwide. YEAR: 2017. REFERENCES: Organ and Tissue Procurement From Non-residents Deceased in Poland: Guidelines for Transplant Coordinators. Transplant Proc 2018 (in press). https://doi.org/10.1016/j.transproceed.2018.03.130

Events that might have had an impact on organ donation

QUESTION: Please provide a short description of events that supposedly had a positive or negative influence on organ donation.

Table 14: Events with a possibly positive/negative influence

	Major event(s) that supposedly had a positive influence:	Major event(s) that supposedly had a negative influence:
Belgium	Witness testimonies of transplantation patients and donor families. European organ donor day (media attention). Cinema "Réparer les vivants", promotional film shown at festivals. Positive influence of politicians and journalists.	None
Czech Republic	TV series (five parts) broadcast by the biggest Czech TV channel in cooperation with Prague transplant centre, 2012	
Italy	From 2001, the Italian Ministry of Health has promoted national campaigns in order to increase organ donation and transplantation awareness among citizens. The Italian Ministry of Health encourages people to express their will on organ donation and cooperates with the Italian National Transplant Centre and with Associations to fulfil campaigns. We have never planned measurement initiatives in order to establish a correlation between national campaigns and donation rate. Since 2013 it has been possible to express the will to donate at the time of renewal of the ID card. As of October 17th 2018, 2 508 158 people had registered, 1 835 613 expressing positive consent (73.2%) and 672 545 negative consent (26.8%). In recent years the story of Nicholas Green, a child who died while he was on holiday with his family in Italy, positively opened the discussion about organ donation, and there have also been increasing numbers of living donors proposing themselves as Samaritan donors.	- In February 2007 (Careggi Hospital-Florence) the liver and kidneys from an HIV-positive woman were transplanted after a laboratory biologist mistakenly wrote on the woman's medical records that she had tested negative for the virus. In the beginning, this tragic human error was reported by the Italian media as a case of malpractice, poor hygiene and poor safety standards; thanks to a transparent communication made by clinicians of Careggi Hospital (coordinated by the Italian National Transplant Centre) the media started focusing their attention on the cause of this dramatic accident: a human error. - In February 2010 CNT managed three cases of "Samaritan donors" who wanted to donate their kidney to an unrelated recipient (even though the Italian law regarding living donation establishes that it should be an identified recipient the donor knows). These cases immediately gained the attention of the Italian media (newscast, newspapers, magazines, etc.) and were covered for several months. - In December 2008 the Italian media focused on the case of a young woman who had been in a permanent vegetative state since a car accident in 1992. Her father had started a legal battle in order to be authorised to carry out the most difficult and tragic action of his life: honouring his daughter's wish to die rather than be kept alive artificially. In those days, media attention on the controversy was incessant: a few articles reported misleading information confusing "brain death" and "permanent vegetative state". In response, the Italian Ministry of Health and Italian National Transplant Centre organised a press conference, giving scientific and technical information on the difference between "brain death" and "permanent vegetative state" which had caused confusion among Italian people.
Latvia	Introduction of transplantation coordination in the practice of the Latvian Transplantation Centre. Specialisation in transplantology (fellowship after graduation and certification in surgery)	Limited budget overall (and budget cuts since financial crisis) with limitation in the number of state-financed kidney and heart transplantations, no budget for liver (started in 2018) and lung transplantation, or for other

	Annual meetings with ICU personnel (during 2014-2017 arranged twice a year) focusing on information about the previous year's results, the main topics in transplant medicine and science, problems in Latvia and foreign experiences. Positive publications and movies about transplantation	programs. Restructuration of the Latvian Transplantation Centre (separation of transplant coordination and laboratory from the central structure, expected closure of special department for kidney transplantation). Negative publications and movies about transplantation
Lithuania	In 2014 the Games for People with Transplanted Organs were organised in Lithuania by the Patient Organisation "Gyvastis". Presentations and demonstrations of the donation-transplantation process organised by the NTB 2013-2014 together with contributions from the State Border Guard Service, the Air Force, police and ambulance services. In 2017, the performance of I. Matijošaitienės Foundation "I am dying but I want to live" with extensive social advertising. Media support for donation, NTB organises events for the media by presenting the donation and transplantation process: providing the opportunity to visit ICUs and talk with doctors and recipients after transplantation. NTB constantly provides statistics and other information, not only on the website, but also by sending them to individual regions;	2012 liver transplantation case where surgeons in one transplant centre arbitrarily decided that transplantation would be at their centre, since the donor organ was in their hospital; they circumvented the recipient order and the liver was not transplanted to the first recipient on the list; 2018 The proposal of a politician, Member of the Parliament of the Republic of Lithuania, to introduce a presumed consent model in Lithuania prompted a number of negative discussions; In all cases, the NTB spent a lot of time communicating, answering questions, providing comments, writing articles, etc. Ultimately this had no negative impact on donation.
Republic of Moldova	YEARS: 2014-2016. DESCRIPTION: TWINNING Project "Strengthening the Transplant Agency of the Republic of Moldova and support in legal approximation in the area of quality and safety of substances of human origin" was implemented. Results achieved: the overall Moldovan legislation related to the transplant of human organs, tissues and cells is in compliance with EU and international standards and norms; increased staff knowledge, practice and skills of all involved institutions; the transplant system of the Republic of Moldova is in compliance with the best quality standards and public expectations; a communication and information campaign addressing health care professionals, other professional groups/civil society, general public (communication materials, seminars, etc.). IMPACT: major/positive; donation rates increased in the following years.	
Netherlands	In 2007: Dutch Donor Show. DESCRIPTION: There was a TV programme about a woman who had a brain tumour and wanted to choose the recipient to whom she would donate her kidneys after death. The recipients were on the show and tried to convince the donor to choose one of them. There was enormous media attention on a national and international level. It resulted in high numbers of donors that year, political attention for donation and resources to start the Masterplan for Donation. In 2018: Dutch decision to transfer to an Opt-out system. DESCRIPTION: The consent system in the Netherlands will change from Opt-in to Opt-out on 1st July 2020. IMPACT: clear position on donor preferences of the potential donor, clear role for next of kin in consent process, leading to more consent for organ and tissue donation and more donors.	Year: 2016. DESCRIPTION: Family of an organ donor sued the transplant coordinator and procurement surgeon because they thought they had not been well informed. IMPACT: a lot of negative reactions on social media and distrust about donation.
Slovakia	no	no

Slovenia	European organ donation day celebration with recipients' stories, some TV programmes featuring discussion between experts, and results in transplant medicine.	Some cases could be very influential and resounding; however, in Slovenia we have not had a lot of them and none that were particularly important or influential.
Spain	Annual statistics on donation and transplantation	Frustrated attempts of organ trafficking
Switzerland	2017: Switzerland hosted the EODD.	2012-13: Media reports about irregularities in liver allocation in some German transplant centres. It is unclear whether the media coverage impacted the donation activity in Switzerland. However, a decrease in the consent rate of 9 percentage points was observed during the first six months of 2013. 2007: Coming into force of the National Transplantation Act; change to nationwide explicit consent (before: 17 cantons with presumed consent, 7 cantons with explicit consent). 2007: Trial of the R. Voser case (patient who in 2004 was transplanted by mistake with an ABO-incompatible heart graft and subsequently died).
United Kingdom	YEAR 2015 DESCRIPTION The story of Teddy, the UK's youngest deceased organ donor (at the time). Born with anencephaly. Lived for 100 minutes. Proceeded to DCD. http://www.itv.com/news/wales/2015-04-23/baby-teddy-was-britains-youngest-organ-donor-a-short-but-heroic-life/ https://www.mirror.co.uk/news/uk-news/footage-shows-britains-youngest-organ-7126972 IMPACT His Parents won a Pride of Britain award. https://www.mirror.co.uk/news/uk-news/our-boy-lived-died-hero-6556361 Survey following Pride of Britain awards in 2015 • An estimated 4.3 million adults said it made them think whether they would want their own children to be organ donors. • An estimated 5.6 million adults agreed Teddy's story made them think about whether they wanted to donate their organs after they die. • An estimated 3.3 million adults agreed that Teddy's story led them to talk to friends and family about donating their organs after they die. Increase of 112 286 new registrations on the NHS Organ Donor Register.	YEAR 2014 DESCRIPTION Two kidney transplant recipients died after donor transmission of a rare parasite. https://www.theguardian.com/society/2014/de/c/04/transplant-patients-died-kidney-worm IMPACT Potentially increased caution by transplant surgeons. The year that followed was the only year deceased donation has not risen in the UK over the last ten years. It is very likely that this was multifactorial, but DCD seems to have been more specifically affected.

Outlook

QUESTION: What further measures could improve the donation activity in your country?

Table 15: Further measures that could improve organ donation

Belgium	Every year the same deployment requirements of hospitals and government! Maybe organisation of the European Donor day again
Czech Republic	More transplant coordinators in donor hospitals, further development of DCD and living donation.
Italy	Increase the number of centres performing DCD and increase living donation through the development of the national KEP.
Latvia	Improvements in legislation (introduction of DCD III category with withdrawal of life-sustaining therapy - currently not allowed by legislation) Improvement of public awareness Improvement in education of medical workers and in society
Lithuania	From the year 2019, the Office will provide lectures on "Fundamentals of Organ Donation" for doctors together with Vilnius University - a 3-hour certificate will be issued. Even more reanimatologists will expand their knowledge. Contact with TPM course organisers on the possibility of organising courses for doctors in Lithuania – funding is being sought for the Spanish proposal. Health Minister legal act for donors after cardiac death will expand donor organ pool
Republic of Moldova	DOMAIN: Detection and referral of possible donors. AIM: Strengthening and expanding the transplant coordination service by means of creating a national coordination system for organ and tissue procurement with the expansion of authorised medical institutions and the creation of North and South Donor Centres. It will be implemented at national/regional level. STATUS: Implementation has already started.
Netherlands	DOMAIN: Obtaining consent. AIM: new way of organising donation in the Netherlands. Dedicated persons will be involved with all potential organ donors and they will guide the family through the consent process. STATUS: the new organisation is planned to be implemented in 2020.
Poland	1. External audits of donor hospitals on the subject of donor recruitment in connection with the hospital quality assurance program. 2. Changes in law: obligatory info to Poltransplant in every case of death and/or severe brain damage. 3. Criterion "to have hospital organ donation quality system" when hospitals apply for accreditation.
Slovakia	Changes in law to allow DCD program
Switzerland	- Swisstransplant will launch a national organ donation registry for the voluntary registration of consent/objection to organ donation in October 2018. - Signatures are being collected by an independent group for a popular vote on changing the consent policy to presumed consent.
United Kingdom	DOMAIN Obtaining consent AIM Legislative change is being actively explored in England and Scotland to move to a system of presumed consent (soft opt-out). STATUS Within parliamentary processes in Scotland and England.

Additional information

Consent policy

QUESTION: What is the consent policy?

Table 16: Overview on consent policies

	Belgium	Czech Republic	Estonia	Italy	Latvia	Lithuania	Republic of Moldova	Netherlands	Poland	Slovakia	Slovenia	Spain	Switzerland	United Kingdom
Presumed consent (opt-out)														
Explicit consent (opt-in)						X								

X = no family veto allowed

QUESTION: If the consent policy has been changed during the study period, please indicate the year when the above policy came into force.

Table 17: Details on changes of the consent policy

Latvia	Legislation is currently under review
Switzerland	2007 (before the coming into force of the National Transplantation Act, 17 cantons had a presumed consent policy and 7 cantons an explicit consent policy).
United Kingdom	Before 2015 all UK explicit consent (opt-in) and although no family veto was allowed in law, in practice it is allowed. If there is no opt-in, family decide. Since 2015 Wales has had deemed consent (presumed consent) and family veto allowed.

Family approach

QUESTION: Please provide a short description of the setting and timing of family approach.

Table 18: Setting and timing of family approach

Belgium	First brain death, then check register and then contact family (IC doctor, nurse TX coordinator) We ask about the will of the deceased person, NOT the will of the family! Family conveys the will. It is important to always give feedback to the family after the procedure. Respect for the feelings of the family is high priority!
Czech Republic	ICU doctor contacts family before brain death
Estonia	Mainly after confirmation of death, in rare cases before

Italy	The family approach usually takes place in the transplant coordinating office, in a quiet and separate room. Two health professionals, namely a hospital coordinator and a nurse, and the coordinator for organ donation approach the family. The family approach starts after the declaration of death when the potential donor is referred from the ICU.
Latvia	In the past, family approach was usually performed by the organ retrieval team (transplant surgeons and coordinators), but currently it is more often done by ICU personnel or regional coordinators (when possible). In most cases the first information about bad prognosis and awaited diagnosis of brain death is given by an ICU doctor during the brain death protocol, and the interview about the donation takes place after the brain death declaration. In cases with progressive worsening of the condition and risk of cardiac arrest, the interview can take place before the declaration of brain death.
Lithuania	The request is almost always made by the reanimatologist doctor who treated the patient, and the talk takes place after brain death. Short description of family veto: family veto is not allowed in Lithuania (Health minister legal act), but we had one case where the dead patient had a donor card, but relatives said that they did not know that and were very angry at the doctors. The decision was made that the dead patient would not be a donor, because of the scandal of the relatives.
Republic of Moldova	The family approach takes place in a separate room close to the ICU. The person who is making the request is the transplant coordinator (anaesthesiologist, 8 health care professionals). The family interview is performed after brain death diagnosis is completed.
Netherlands	Families are approached after treatment is deemed futile and the death of the patient is expected.
Poland	Family approach takes place in every case of an eligible donor and always after death confirmation and after checking whether opposition to donation exists or not in the central refusal registry.
Slovakia	If there is confirmed brain death there is an interview between the family and the transplant coordinator.
Slovenia	The family interview about donation is performed after brain death is confirmed. Usually it is carried out in combination by two doctors. The ICU doctor is in charge of giving the bad news to the family and the coordinator comes in afterwards with the request for donation. It is recommended that both stay together from the beginning until the end of interview, but unfortunately this is not regular practice in all hospitals and ICU doctors often leave the coordinator alone with the family.
Spain	Classically, the family approach was only done once the person had achieved a clinical condition consistent with brain death or when brain death had already been diagnosed. This is now changing. At present, the family approach takes place at different times, taking into account the clinical condition of the patient and the pace of the family in understanding and requesting information (individual approach). Hence, it is becoming normal practice to make the family approach when the decision is made to withdraw life-sustaining therapies on the grounds of futility of further care, either inside or outside of the ICU.
Switzerland	There is no nationally standardised setting and timing of family approach.
United Kingdom	Case Vignette example. Michael, a 54-year-old male, suffered a devastating brain haemorrhage and was admitted to a regional neurosurgical centre. Sadly, there was no treatment option and he showed no signs of recovery. Two days later on the intensive care unit (ICU), Michael's Glasgow Coma Score (GCS) off sedation is 3/15, his pupils are fixed and non-reactive to light, his cough and gag reflex are absent, and he is taking no spontaneous breaths on the mechanical ventilator he is attached to. His intensive care doctors suspect he has already died at some point over the last 24 hours. A plan is made to carry out formal bedside tests of Michael's brainstem function to diagnose and confirm death using neurological criteria (brainstem death). A family discussion is planned. Prior to these tests and family discussion, a referral to the specialist nurse for organ donation (SN-OD) is made. The SN-OD has an office near the ICU and consults the NHS Organ Donor Register; Michael registered three years ago via the DVLA when he renewed his licence. The SN-OD reviews Michael's medical records and no initial contraindication for exploring DBD is discovered. This knowledge prevents families being offered donation when there is no realistic chance of it going ahead. Additionally, the SN-OD is an expert in supporting families through the confirmation of death and bereavement care, as well as her donation role. The ICU doctor, Michael's bedside nurse, and the SN-OD plan how they will explain to the family the terrible suspicion that Michael has already died. The ICU doctor then leads the discussion with the family, with the support of Michael's bedside nurse and the SN-OD, and helps the family to understand the concept of death using neurological criteria (brainstem death). The ICU doctor explains that bedside examination and testing of Michael will be carried out by two senior ICU doctors and this examination will be performed twice. The tests are expected to confirm that Michael has already died. The family are offered the chance to witness the second set of tests. The ICU doctor and bedside nurse leave to commence the tests. The SN-OD remains to support the family. After the first sets of tests, which reveals no brainstem function, the ICU doctor speaks again to the family to share this sad news and to see if they wish to witness the second set of tests. They do. With the support of the bedside nurse and SN-OD they are present during the second and final examination of Michael by the two doctors. The simple but powerful tests are designed to detect if Michael has any brainstem function and includes examining Michael to see if: his pupils react to light, he blinks, he reacts to stimulus within his head, he coughs or gags, his eyes react to 50 ml of ice cold water gently syringed into his ear canals, and if he can breathe when taken off the mechanical ventilator. He can do none of these things and the two doctors diagnose and confirm that Michael has died.

	Ongoing end-of-life care is planned with Michael's family. As part of this discussion the SN-OD informs the family that Michael was registered on the NHS Organ Donor Register and had consented for donation to occur after his death. The family are in agreement and knowing that they can respect an end-of-life wish of Michael's, as well as help others, brings them some comfort. After signing the donation paperwork and after answering the SN-ODs donation safety questions, the family say goodbye to Michael and head home. Twenty hours later, while Michael is still on the mechanical ventilator and his organ function maintained during this period, he is transferred to theatre and donates his heart, lungs, liver, pancreas and both kidneys.
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Registry

QUESTION: Is there a registry in your country?

Table 19: Overview on registries

	Belgium	Czech Republic	Estonia	Italy	Latvia	Lithuania	Republic of Moldova	Netherlands	Poland	Slovakia	Slovenia	Spain	Switzerland	United Kingdom
There is a registry														
for people who wish to donate														
for people who DO NOT wish to donate														
NO registry / other												X	#	

^x There is an advanced directives registry where persons can register their will to become or not become an organ donor after death.

[#] A national organ donation registry (voluntary registration of consent or objection) was introduced by Swisstransplant in October 2018.

(For details on registries, see next page)

Table 20: Details on registry

Belgium	A registry for people who wish to donate their organs; a registry for people who DO NOT wish to donate their organs.
Estonia	NO REGISTRY.
Italy	A registry for people who wish to donate their organs; a registry for people who DO NOT wish to donate their organs.
Latvia	A registry for people who wish to donate their organs; a registry for people who DO NOT wish to donate their organs.
Lithuania	A registry for people who wish to donate their organs; a registry for people who DO NOT wish to donate their organs.
Republic of Moldova	A registry for people who DO NOT wish to donate their organs.
Netherlands	4 options: consent, refusal, decision by relatives, decision by a specified person
Poland	A registry for people who DO NOT wish to donate their organs.
Slovakia	A registry for people who DO NOT wish to donate their organs.
Slovenia	A registry for people who wish to donate their organs; a registry for people who DO NOT wish to donate their organs.
Spain	There is an advanced directives registry where persons can register their will to become, or not, an organ donor after death
Switzerland	NO REGISTRY. A national organ donation registry (voluntary registration of consent or objection) will be introduced by Swisstransplant in October 2018.
United Kingdom	A registry for people who wish to donate their organs; a registry for people who DO NOT wish to donate their organs.

QUESTION: If there is a registry, please provide a short description.

Table 21: Description of registry

Belgium	1986, press + TV debate. Registration is not mandatory. This year a law may be passed to allow registration by ID-card or by GP (eHealth)
Czech Republic	Non-donor register since 2002; optional
Italy	In Italy there is a combined registry. People can express their consent or objection to organ donation and this is registered in the Italian transplant IT system. Registrations are made directly at the office of the local health authorities, through the donor association or, since 2016, at the renewal or first issue of the ID card. Registration is optional even in this last case.
Latvia	Registry (currently State Population registry, from 2020 - e-health registry) has been in place since 2004. Information for population dispersed by mass-media (TV, radio, press) arranged mainly by the Latvian Transplantation centre. Registration is optional.
Lithuania	NTB operates the Registry. It was implemented in 2000 by the Government resolution. Donor card registration is available through the electronic gateway or in paper form. Doctors who treat recipients and who diagnose brain death can access the Register with a password. Mandatory.
Republic of Moldova	The YEAR of introduction: 2014. The Transplant Agency operates the registry. The procedure of registration is under development.
Netherlands	The donor register was implemented in 1998 when the Dutch donor Act came in force. All inhabitants were asked to register their donor preferences. There is a yearly campaign for all persons who become 18 that year and for all new inhabitants, who receive a registration form. Registration is possible from age 12 and takes place online. Partly opting out of certain tissues and organs from consent is possible. Registration is not mandatory; however in 2020 this will change.
Slovakia	National transplant organisation
Slovenia	Slovenija transplant is the data manager, and the data are stored with other population data at National public, insurance company. We started the registry in 2003. The media are constantly publishing data on how the declaration for donation could be made – the declaration for or against donation is made on a voluntary basis, is optional and not many Slovenian people have made a declaration (less than 1%).
United Kingdom	Commenced 1994 Managed by NHSBT Majority of registrations come from driving licence renewals and first applications. Also, from GP surgery registration, Boots advantage card and online. Registration is voluntary.

	The NHS Organ Donor Register was set up to co-ordinate supply and demand following a five-year campaign. Despite millions carrying donor cards there had been no single database of those who had pledged their organs for transplant. With the launch of the Organ Donor Register it is far easier to identify a donor's wishes, and allows the public to sign up as organ donors in new ways, such as on driving license applications. The scheme is a resounding success, with more than 2.2m having joined the database by the end of 1995. By 2018 25 million people were registered.
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Programme participation

QUESTION: Please indicate in which Council of Europe and/or European Union programmes related to organ donation and transplantation your country has participated or is participating.

Table 22: Programme participation

Belgium	Working together with Eurotransplant
Czech Republic	MODE, ACCORD, DOPKI, COORENOR, BLACK SEA AREA, FOEDUS
Estonia	EUROCET, etc.
Italy	CD-P-TO meetings and preparation of Guides for quality and safety (organs, tissues and cells), EU competent authority meeting, EUDONORGAN project, FOEDUS cooperation agreement for organ exchange
Latvia	COORENOR MODE ACCORD Seeding life
Lithuania	ETPOD, COORENOR, TPM, MODE, ACCORD, FOEDUS
Republic of Moldova	COORENOR, FOEDUS
Netherlands	ACCORD, EFRETOS, COST, EDITH
Poland	DOPKI, ODEQUS, EUROCET, EULID, COORENOR, FOEDUS, ETPOD, ACCORD
Slovenia	EDD, ACCORD, EUSTITE, FOEDUS, EUROCET, ETPOD, EULID, EUDONORGAN, GUIDELINES (CoE), many other documents and publications discussed at the CD-P-TO meetings, DOPKI, EFRETOS
Spain	ALLIANCE-O, DOPKI, MODE, COORENOR, ACCORD-JA; EFRETOS, and many other EU funded projects. The country is highly active in all initiatives organised by the Council of Europe and the European Union.
Switzerland	DOPKI, COORENOR/FOEDUS, EDITH, ACCORD, ODEQUS, EULID
United Kingdom	ACCORD COE initiative for "Prevention of transplant-related crime" COST "European Network for Collaboration on Kidney Exchange Programmes" (ENCKEP) project FOEDUS ODEQUS COPE

QUESTION: Comments on the survey questionnaire.

Table 23: Comments on the survey

Spain	The basis of the Spanish Model for Organ Donation and Transplantation, as widely described in the literature, has been essential to the Spanish success over the years, along with vision, dedication and leadership. For more information, please review: - Matesanz R, et al. The 40 donors per million population plan: an action plan for improvement of organ donation and transplantation in Spain. <i>Transplant Proc.</i> 2009 Oct;41(8):3453-6. - Matesanz R, et al. Spanish experience as a leading country: what kind of measures were taken? <i>Transpl Int.</i> 2011 Apr;24(4):333-43. - Matesanz R, et al. Benchmarking in the process of donation after brain death: a methodology to identify best performer hospitals. <i>Am J Transplant</i> 2012 Sep;12(9):2498-506. - De la Rosa G, et al. Continuously evaluating performance in deceased donation: the Spanish quality assurance program. <i>Am J Transplant</i> 2012 Sep;12(9):2507-13. - Matesanz R, et al. Benchmarking in organ donation after brain death in Spain. <i>Lancet.</i> 2012 Aug 18;380(9842):649-50. - Matesanz R, et al. How Spain Reached 40 Deceased Organ Donors per Million Population. <i>Am J Transplant.</i> 2017 Jun;17(6):1447-1454. - Domínguez-Gil B, et al. End-of-life practices in patients with devastating brain injury in Spain: implications for organ donation. <i>Med Intensiva.</i> 2017 Apr;41(3):162-173. - Domínguez-Gil B, et al. Expanding the Donor Pool Through Intensive Care to Facilitate Organ Donation: Results of a Spanish Multicenter Study. <i>Transplantation.</i> 2017 Aug;101(8):e265-e272.
United Kingdom	None

Annex

Donor conversion index (DCI) of survey participants

DCI evolution by country, 2001-2015.



Blue bars, DBD; purple bars, DCD; grey bars, no distinction between DBD and DCD in Newsletter Transplant database (no bars: missing donor data or no donors reported). No country chart available for Republic of Moldova.

SOURCE: Weiss J, Elmer A, Mahillo B, Domínguez-Gil B, Avsec D, Costa AN, Haase-Kromwijk BJJM, Laouabdia K, Immer FF, on behalf of the Council of Europe European Committee on Organ Transplantation (CD-P-TO). Evolution of deceased organ donation activity vs. efficiency over a 15 year period: an international comparison. Transplantation. 2018;102(10):1768–78 [Figure 2].