ACHIEVING COMPREHENSIVE COORDINATION IN ORGAN DONATION THROUGHOUT THE EUROPEAN UNION

ACCORD

A JOINT ACTION CO-FUNDED BY THE EUROPEAN COMMISSION

Background

Organ transplantation (OT) benefits about 28,000 patients in the European Union EU yearly, but the availability of organs does not meet the OT needs, unequally met by MS, mainly due to variability in living and deceased donation rates. This heterogeneous scenario and the need to establish a common framework for quality and safety of human organs intended for OT, has led to two EU initiatives in the field: Directive 2010/53/EU (the Directive) and an Action Plan, both to be addressed by this Joint Action (JA) through intervention in 3 areas: live donor registries, cooperation between intensive care units (ICUs) and donor transplant coordinators (DTCs) and twinning. Live donation activity is increasing in the EU to better meet the OT needs. But the live donor faces risks which make mandatory an appropriate framework of donor care in compliance with universal standards. These include the development of a live donor registry, as set down in the Directive, essential to build evidence on the consequences of donating an organ during lifetime, but not yet available in many MS. The main reason justifying differences in deceased donation rates across countries is failure to identify potential organ donors. A close cooperation between ICU professionals, dealing with end-of-life care, and DTC, is fundamental to possible donors becoming actual donors, as put forward in the WHO critical pathway. Nevertheless, the integration of donation in end-of-life care remains a challenge. Providing recommendations on how to build this integration, based on a benchmarking approach, has proven effective in different countries, but must be respectful with differences in end-of-life patterns of care. Finally, international cooperation is per se considered an effective tool to improve performance in donation and OT practices. Twinning activities may promote that the experience and knowledge developed by one MS is transferred to others who request such transference and will implement the advance willingly.

What is ACCORD?

The project **"Achieving Comprehensive Coordination in Organ Donation throughout the European Union- *ACCORD*"**, is a Joint Action (JA) submitted and

approved by the call for proposals 2011 of the Health Programme 2008-2013, DG SANCO (European Commission).

With a duration of 42 months, the project lifetime extends from May 2012 to November 2015. The kick-off meeting of ACCORD was held in Madrid (Spain) on May 31st, 2012.

Objectives

ACCORD intends to strengthen the full potential of Member States (MS) in the field of organ donation and transplantation in order to improve the cooperation between them and to contribute to the effective implementation of the *EU Directive 2010/53/EU* and the *Action Plan on Organ Donation and Transplantation (2009-2015): Strengthened Cooperation between MS*. In particular, ACCORD intends to:

1. Improve MS information systems on live organ donation through the provision of recommendations on the design and management of structured live organ donor registries and through setting down a model for supranational data sharing in this field.

2. Describe the usual pathways applied to patients with a devastating brain injury and to explore their impact on the potential of donation and on the realization of the deceased donation process across European Union (EU) countries.

3. Develop and prove by implementation an acceptable and effective rapid improvement toolkit that supports modifications in end-of-life management that promote donation, adapted to each identified end-of-life care model.

4. Implement practical collaborations between EU countries for the transfer of knowledge, expertise or tools in specific areas related to the *Directive 2010/53/EU* and the *Action Plan on Organ Donation and Transplantation (2009-2015)*, based on comprehensive and specifically prepared protocols.

5. To provide recommendations for future twinning initiatives in organ donation and transplantation.

6. To disseminate and ensure the sustainability of the results and products of the ACCORD project.

The Consortium

ACCORD will be implemented by a consortium conformed by 23 Associated Partners, the Organización Nacional de Trasplantes (Spain) acting as Project Coordinator. Moreover, 9 organizations and institutions will participate with the role of Collaborating Partners.

❑ Project partners (Coordinator and Associated Partners)

COUNTRY	ORGANISATION	
SPAIN	ORGANIZACIÓN NACIONAL DE TRASPLANTES (ONT). **Coordinator**	Project Leader and WP 1 & WP 3 leader
ITALY	INSTITUTO SUPERIORE DE SANITÁ, CENTRO NAZIONALI TRAPIANTI (ISS-CNT)	WP 2 leader
THE NETHERLANDS	NEDERLANDSE TRANSPLANTATIE STICHTING (DUTCH TRANSPLANTATION FOUNDATION)	WP 4 leader
UK	DEPARTMENT OF HEALTH, ORGAN AND TISSUE TRANSPLANTATION – NHS (NHSBT)	WP 5 leader
FRANCE	AGÉNCE DE LA BIOMEDICINE (ABM)	WP 6 leader
BULGARIA	BULGARIAN EXECUTIVE TRANSPLANT AGENCY (BEAT)	
CROATIA	MINISTRY OF HEALTH AND SOCIAL WELFARE OF THE REPUBLIC OF CROATIA, DEPARTMENT FOR SPECIAL HEALTH CARE AND TRANSPLANTATION (MOHSW)	
CYPRUS	MINISTRY OF HEALTH	
CZECH REPUBLIC	CZECH TRANSPLANTATION COORDINATION CENTER (KST)	
ESTONIA	PERMANENT REPRESENTATION OF ESTONIA TO THE EU / TARTU UNIVERSITY HOSPITAL (TUH)	
GERMANY	DEUTSCHE STIFTUNG ORGANTRANSPLANTATION (DSO)	
GREECE	HELLENIC TRANSPLANT ORGANISATION (HTO)	

HUNGARY	HUNGARIAN NATIONAL BLOOD TRANSFUSION SERVICE, HUNGARIAN TRANSPLANTATION SOCIETY (HNBTS)
IRELAND	HEALTH SERVICE EXECUTIVE (HSE)
LATVIA	PAULS STRADINS CLINICAL UNIVERSITY HOSPITAL
LITHUANIA	NATIONAL TRANSPLANT BUREAU (NTB)
MALTA	DG HEALTH CARE SERVICES WITHIN THE MINISTRY FOR HEALTH, THE ELDERLY AND COMMUNITY CARE (MHEC)
NORWAY	THE NORWEGIAN DIRECTORATE OF HEALTH
PORTUGAL	INSTITUTO PORTUGUÊS DO SANGUE E DA TRANSPLANTAÇÃO (IPST)
POLAND	POLTRANSPLANT
ROMANIA	NATIONAL TRANSPLANT AGENCY (ANT)
SLOVENIA	SLOVENIJA TRANSPLANT
SWEDEN	NATIONAL BOARD OF HEALTH AND WELFARE (SoS)

❑ Collaborating partners

ORGANISATION
WORLD HEALTH ORGANISATION
EUROPEAN DIRECTORATE FOR THE QUALITY OF MEDICINES AND HEALTH CARE, COUNCIL OF EUROPE
EUROPEAN HOSPITAL AND HEALTHCARE FEDERATION (HOPE)
EUROPEAN SOCIETY OF INTENSIVE CARE MEDICINE (ESICM)
EUROPEAN TRANSPLANT COORDINATORS ORGANISATION – EUROPEAN DONATION COMMITTEE- ETCO-EDC, a section of ESOT
EUROTRANSPLANT
SCANDIATRANSPLANT
HOSPITAL CLÍNIC i PROVINCIAL, ASESORÍA DE TRASPLANTES
ORGANISATION DES ÉTABLISSMENTS DE SOINS, BELGIUM

Phases and Project organisation

The organisation of ACCORD requires a combination of working methods distributed among two types of Work Packages (WPs), horizontal and core WPs. Each one of the WPs will be coordinated by one of the Associated Partners.

The main objective of the WPs is described below:

- **Horizontal WPs:**
  1. **Coordination of the project:** To manage the project and make sure that it is implemented as planned. **(WP leader: ONT, Spain)**
  2. **Dissemination of the project:** To ensure that the results and deliverables of the project will be made available. **(WP Leader: ISS-CNT, Italy)**
  3. **Evaluation of the project:** To verify whether the project is being implemented as planned and reaches its objectives. **(WP Leader: ONT, Spain)**

- **Core Work Packages:**
  4. **Living Donor Registries:** To provide recommendations on the implementation of live donor registries and to set down a model for supranational data sharing. **(WP Leader: DTF, the Netherlands)**
  5. **Intensive Care Units (ICUs) and Donor Transplant Coordinators (DTCs) Collaboration:** To analyse end-of-life practices across Europe and their impact on organ donation and to provide a rapid improvement methodology for strengthening cooperation between ICUs and DTCs. **(WP Leader: NHSBT, United Kingdom)**
  6. **Twinning in Organ Donation and Transplantation:** To implement specific collaboration initiatives between EU countries in the area of organ donation and transplantation according to national priority actions and to develop guidelines for future twinnings in this field. **(WP Leader: ABM, France).**

Deliverables

N	TITLE	DESCRIPTION
1	**Manual for the financial and administrative management of the JA and reporting period reports (3)**	Manual establishing rules and procedures for the financial and administrative management of the JA. Reports addressing financial and administrative issues will also be delivered for three reporting periods: First (M1-M12), second (M13-M24) and final.
2	**Project web site and internal working section**	A dedicated project website including a public space for dissemination activities and a site for internal communication.
3	**Plan and tools for dissemination and sustainability**	A strategy and communication plan will foresee the development of at least 2 newsletters targeted to the scientific community and 2 brochures for the general public and decision makers. A sustainability plan will also be released by each participant.
4	**Evaluation system and evaluation reports**	An oriented results follow-up system will be devised at the beginning of the project, foreseeing periodical progress reports (2) and a final external evaluation report. A report prepared by the EAB is planned to be released at the end.
5	**Report on the State of the art of live donor registries**	Report compiling information on live donor registries currently in place, either national or international, including details on variables and definitions and governing, operational and technical rules applied.
6	**Recommendations for the development of a LD registry and for setting up a EU registry of LD registries. Report on pilot study**	Report providing recommendations for developing a live donor registry in terms of design and rules. Separate report with recommendations for international data sharing, based on the concept of a registry of live donor registries. Description of a pilot study on the international data sharing.
7	**Report on the study of the variations in end-of-life care pathways for patients with devastating brain injury in Europe**	Report describing end-of-life-practices for patients with a devastating brain injury and their impact on the potential of deceased donation and the realization of the deceased donation process in the EU, based on a dedicated study on a sample of hospitals.
8	**Recommendations for improvement and toolkit methodology: systemic improvements in end-of-life care pathways to promote OD**	Report providing recommendations to be applied to end-of-life care pathways for promoting organ donation.
9	**Report on experiences with Twinning Projects in ACCORD (description of each twinning, including proposal and report)**	Two reports will be generated. One of them will describe the individual twinning initiatives developed in ACCORD and a second one issued later on will summarize the overall experience with twinnings during the JA.
10	**Guidelines for Twinning Projects on organ donation and transplantation practices in the EUL**	Report providing recommendations for further twinning initiatives to be developed in the area of organ donation and transplantation beyond the project lifetime.

Expected outcomes

1. Recommendations for setting up living donor registries will be provided, facilitating international data sharing, which will provide Member States without living donation with standards and expected results. Living donor registries will increase the safety of live donor programmes.

2. The variability in end-of-life practices applied to brain injured patients and their impact on organ donation will be described, the areas for improvement identified and an ad hoc toolkit methodology designed. Training to achieve repeatable rapid improvements will be provided. The donor potential is expected to expand and the deceased donation process to be optimized.

3. Through twinnings, the expertise or tools developed by a Member State are to be transferred to other/s requesting it, depending on the areas to be reinforced on the Member States involved. A model for further twinning actions will be built, facilitating new initiatives in the field.

4. Consistent implementation of the Directive 2010/53/EU and the Action Plan on Organ Donation and Transplantation (2009-2015), as well as cooperation between Member States in the field will be facilitated.

Funding

This Joint action is co-funded by the European Commission – 60% and the participating countries – 40%. The total budget is 2 435 123 €.