

## ACHIEVING COMPREHENSIVE COORDINATION IN ORGAN DONATION THROUGHOUT THE EUROPEAN UNION: ACCORD

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### INTRODUCTION

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. Developed by a Consortium of 23 Associated Partners and 10 Collaborating Partners, this JA is developed under the leadership of the Spanish National Transplant Organization (ONT).



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### MANAGEMENT

WPI is aimed to manage and coordinate the project and make sure that it is implemented as planned, managed following the European Commission's rules and procedures, and funded through a correct distribution, execution and justification.

During the whole ACCORD JA and in its role of Coordinator, ONT has to:

1. *Coordinate the project*: leading the design of the work packages (WPs) in close collaboration with the corresponding WPs leaders, supervising vertically the work carried out in each WP, assuring the expected deadlines are met and high quality deliverables are produced, assuring permanent exchange of information on WP progress, monitoring transversally the participation of each partner and continuously ensuring the balancing of the activities.

2. *Guarantee quality working procedures*, oriented to results and aims, transparent and balanced within the transnational consortium: designing a General Working Plan for the JA and coordinating specific working plans within each WP, assuring a permanent and transparent communication within the transna-

tional consortium, and dynamizing the JA implementation, motivating all partner organizations for assuring a balanced participation; organizing transnational and coordination meetings.

During the first year, in its role of coordinator, ONT has performed the following tasks:

- *Establishment of project working bodies and procedures*. Different roles comprise a variety of actions: Project director; ONT director - with the overall responsibility for the whole JA, Coordination Unit, constituted by ONT staff monitors the progress of the JA, establishes communication with the WP Steering Committee on a regular basis and reports to the Director of the JA; Project Committee, constituted by all partners involved in the Consortium – main decision making body, WPs Steering Committee, composed of the members of the coordination unit and the leaders of the WPs – operational group in representation of the entire consortium.
- *Development of the Consortium Agreement* including all the commitments in terms of technical and financial aspects, as well as communication procedures, signed by all associated partners.

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### MANAGEMENT

- Production of a Manual for the financial and administrative management of the JA, where the different reporting periods have been defined, along with the management rules and procedures.
- Creation of a web based platform for facilitating the internal communication among the partners and for dissemination purposes.

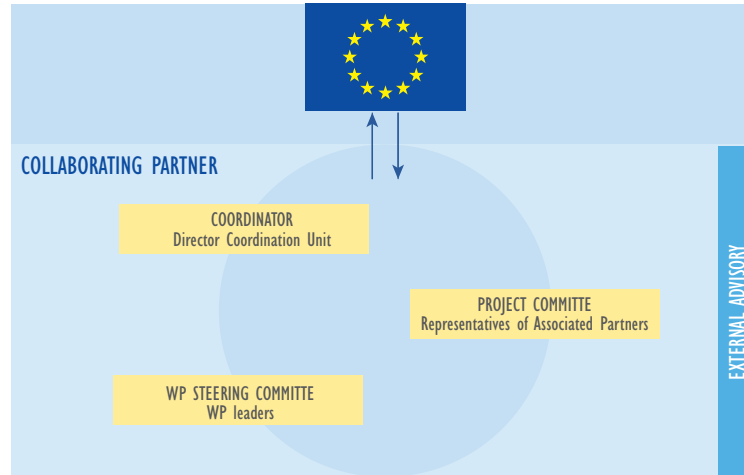


FIG. 1 SCHEME OF ACCORD ACTION MANAGEMENT

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Lead by the Spanish National Transplant Organization (ONT), the aim of the Evaluation work package (WP) is to assure and verify that ACCORD is implemented as planned and that it accomplishes the defined objectives. The WP has also to assure that the produced knowledge and outcomes meet high quality standards, are visible and have a relevant impact.

- The evaluation strategy of the JA has been structured in three main elements:
- An Evaluation System focussed on project processes.
- An External Advisory Board (EAB) focussed on results' quality and future impact of the deliverables produced.
- A comprehensive final evaluation report on both, the project execution and the quality and potential impact of the outcomes.

**1.** The Evaluation System, is oriented on results and follow-up, with two components:

- a periodic collection of information on the developed activities

within the WPs, through the WP leaders, on a half yearly basis;

- an annual report on the progress of the project, including information on the accomplishment of objectives and on any detected deviation. This report mainly aims at including proposals for Improvements Implementation.

**2.** The EAB is composed by three world-wide recognized experts in the field of organ donation and transplantation: Francis L. Delmonico, MD, President of The Transplantation Society; Peter Doyle, MD, United Kingdom and Philippe Morel, MD, Head of the Visceral and Transplantation Surgery at the University Hospitals of Geneva. The EAB aims at assuring and improving the quality of the produced work and the impact of the results and outcomes of ACCORD.

To that end, the EAB: is participating at the general meetings, is reviewing the main deliverables of core WP (4, 5 and 6) to contribute to improve them with comments, suggestions, recommendations, etc... and will elaborate a final report on quality and impact of the JA results.

**3.** A final evaluation will be developed to analyze aims accomplishment, achievement of foreseen objectives, produc-

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tion of deliverables, accomplishment of working plans, the correct running of transnational communication and coordination, the adequacy of working procedures, the success on

implementation of proposed improvements, the dissemination and distribution of the results of the project and, in particular, the transferability and applicability of the results.

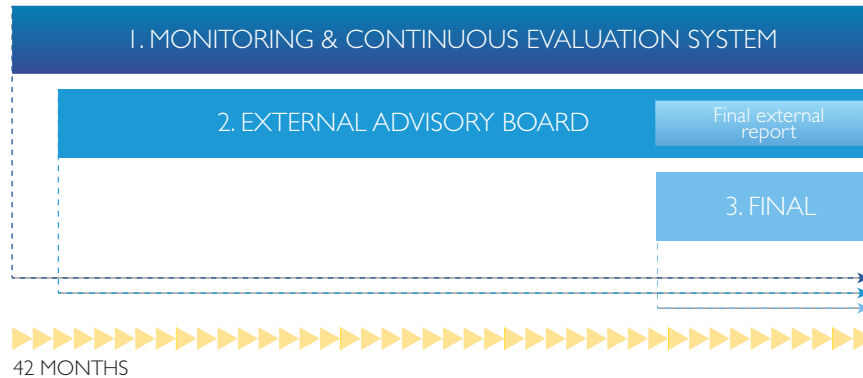


FIG. 2 SCHEME OF EVALUATION WORKPACKAGE TIME SCHEDULE

## ACHIEVING COMPREHENSIVE COORDINATION IN ORGAN DONATION THROUGHOUT THE EUROPEAN UNION: ACCORD

### Living Donor Registries

Objective: to provide recommendations on the implementation of live donor registries and to set down a model for supranational data sharing. (WP Leader: the Dutch Transplant Foundation, the Netherlands).

During the past year, the participating and collaborating partners of WP4 met three times. The first meeting was the kick-off meeting in Madrid where they set the goals and the working plan for the work package. In the summer of 2012, a questionnaire was sent to every partner to collect information on the current status of living donation and the experience with living donor registries. The information from the questionnaire was processed into the first deliverable: a 'Report on the current experience with living donation and living donor registries'.

In November 2012 a second meeting took place in Amsterdam. During this meeting they agreed upon the mandatory and optional datasets for the national living donor registries (kidney and liver) and the datasets for the supranational registry of registries for living donors.

During the third WP4 meeting on February 5th 2013 in Amsterdam, they defined the data dictionary. The data set, data dictionary and glossary of terms were delivered in May 2013.

Next challenge is to describe the governing, operational and technical requirements enabling to start the pilot period and to, eventually, come with recommendations for national living donor follow-up registries and a supranational living donor registry of registries.



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### Cooperation between ICU professionals and donor transplant coordinators

Objective: 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).

The specific aims of the Workpackage are:

- To 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 realisation of the deceased donation process across the European Union (EU) countries.
- To implement an effective rapid improvement toolkit that supports modifications in end-of-life management that will promote donation, adapted to each identified end-of-life care model.

We have recruited 72 hospitals from 15 member states to participate in WP5. A review of the end of life care pathway for patients with a devastating brain injury would be undertaken in each of the 68 participating hospitals.

To achieve this, we devised three questionnaires. Firstly, a country questionnaire was undertaken to examine the legal and ethi

cal infrastructure in relation to organ donation in each participating country. Secondly, a hospital questionnaire was devised to gather information on how organ donation works on a local hospital level and the resources that are present to facilitate organ donation. Finally, a patient questionnaire was developed that enquires about the end-of life care a patient has received who is dying from a devastating brain injury and the impact that care has on the potential for organ donation.

Over the next six months, the WP5 project team will be analysing the patient questionnaires to help participating hospitals to identify where the barriers to organ donation are occurring within their institutions. Three training days on the improvement methodologies are planned over the coming months to which representatives from each of the 72 participating hospitals will be invited.



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### Twinning in Organ Donation and Transplantation

Objective: 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 twinings in this field. (WP Leader: Agence de la Biomédecine, France).

Twinning activities led by the Agence de la Biomédecine in France consist in providing direct support to Member States from one to another by the mean of practical collaborations. Thanks to this concrete transfer of expertise, the overall aim is to enhance day to day Member States efficiency of organ donation and transplantation system.

### Twinning to develop a training programme for organ procurements in Hungary

Supporting country: *Netherlands*

Supported Country: *Hungary*

The first aim of this twinning is to set up a National training programme in organ procurement in Hungary, increasing safety and quality criteria of organs to be transplanted.

Then the 6 Hungarian surgeons followed the training for liver,

kidney and pancreas procurements. Additionally, the Hungarian surgeons completed the first practical session and evaluated information provided by the e-learning platform.

One year after the beginning of this twinning, the e-learning and the first practical session have been completed already and the training-on-the-job procedures are on-going. At the end of the year, the second hands-on session will be held in Hungary, and the Hungarian surgeons will be evaluated by the Dutch trainers.

### Twinning to develop the Bulgarian Transplant system

Supporting country: *France*

Supported Country: *Bulgaria*

The aim of this twinning is to support the development and organization of the organ procurement system at national and regional levels and to sup-



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port paediatric kidney transplantations through the training of the Bulgarian transplant team.

Onsite visits of procurement and transplant centres in Bulgaria and in France were carried on and allowed the French experts to assess the needs of their partners, and Bulgarian experts could experience steps and procedures of the French donation, procurement, allocation and transplant system. A profile and tasks of the hospital donation coordinator were drafted and acted. Then special attention focused on Standard Operating Procedures (SOPs) that are compulsory for the processing of an efficient system, notably ensuring harmonization, compliance with regulation and higher quality and security criteria.

### **Twinning to develop an Authorization and Audit system for Transplant Centres**

Supporting country: *Italy*

Supported country: *Cyprus, Czech Republic, Lithuania and Malta*

This twinning is aiming at developing of an authorization and

audit system for Transplant Centre, based on the Italian model but adapted to each National Health Systems in place.

To start with, each supported country reported on national current status of: i) expected timing of the transposition of Directive 2010/53/EU, ii) designated Competent Authority or delegated organization for organ donation and transplantation iii) existing national Audit System if any, iv) evaluation process in place if any v) all authorized Transplant Centres (name, type, year of authorization), vi) strengths and weaknesses of their system in place. These National reports not only allowed evaluation and comparison of supported countries, but also facilitated harmonization and enabled the Italian partner to design the Guide on Essentials for developing Authorization and Audit systems for Transplant Centre. Moreover onsite Twinning visits of Transplant Centre have been scheduled in July 2013 by the supporting country. As a complement, Italy is supporting twinning in transferring and adjusting the proposed authorization and audit system to their local needs.

"This newsletter arises from the Accord Joint Action (grant agreement n. 2011 21 02) which has receiving funding by the European Union, in the framework of the Health Programme. The sole responsibility lies with the author and the Executive Agency is not responsible for any use that may be made of the information contained herein".

