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Eurotransplant International Foundation – ET
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The Effect of Differing Kidney Disease Treatment Modalities and Organ Donation
and Transplantation Practices on Health Expenditure and Patient Outcomes

Work Packages

Project Coordination - WP1 Leader: DSO
Dissemination - WP2 Leader: OVSz
Evaluation - WP3 Leader: MOH RC
**Treatment modality choices, outcomes and costs for end-stage kidney
disease - WP4** Co-Leaders: AMC on behalf of ERA-EDTA and CNT-ISS
Living Donor Registry - WP5 Co-Leaders: NTS and IDIBAPS
Transplant Recipient Registry - WP6 Co-Leaders: ET and NHSBT

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**The Effect of Differing Kidney Disease Treatment Modalities
and Organ Donation and Transplantation Practices on Health
Expenditure and Patient Outcomes – EDITH**

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Chronic Kidney Disease (CKD) is the cause of substantial morbidity and mortality and results in major burden both to individual patients and society as a whole. Different forms of Renal Replacement Therapy (RRT) exist to treat patients with End Stage Kidney Disease (ESKD), kidney transplantation being one of them. The Pilot Project EDITH, which is co-financed by the European Commission, aims to assess the different treatment modalities for ESKD currently used throughout the EU and to examine the factors that influence the different treatment choices. EDITH supports the establishment of follow-up registries in order to collect crucial information to increase the quality and safety of living donors as well as all transplant recipients.

EDITH is a 36-months project focusing on the differing CKD treatment modalities along with organ donation and transplantation practices and their impact on health expenditures and patient outcomes. The project is subdivided into six closely interlinked Work Packages realized by a multinational interdisciplinary team aiming at long-term sustainability of the registers established.

Treatment modality choices, outcomes and costs for end-stage kidney disease - Work Package 4

There is important variation in practice in the overall management of end stage kidney disease (ESKD) and access to dialysis and renal transplantation in Europe. Within Work Package 4 (WP4) of the EDITH project, the ERA-EDTA Registry in the Academic Medical Center (AMC) in Amsterdam and the Italian National Transplant Center (CNT-ISS) will – together with collaborating stakeholders like renal registries, the European Renal Association-European Dialysis and Transplant Association, the European Kidney Patients Federation, and the French Agence de la biomédecine - address the epidemiology and costs of different treatment modalities for ESKD. This includes the assessment of 1) the frequency of the various treatment modalities for ESKD; 2) factors that influence the choice of those treatment modalities by patients and doctors; and 3) the impact of treatment modality choice on health outcomes like patient survival and quality of life, but also on health care budgets.

Living Donor Registry - Work Package 5

EDITH WP5 is aimed at the realization of a **European Living Donor Registry (ELDR)** for living kidney donors, supporting lifelong follow-up data collection. An important rationale for this development is that EU Member States are both legally (EU Directive 2010/53/EU) and morally obliged to follow-up living donors in order to protect their safety. This Work Package will build upon the recommendations of the former EU Joint Action “Achieving Comprehensive Coordination in Organ Donation” (ACCORD) and it will be realized in close cooperation with WP6. The intended result of this Work Package is a supranational ELDR, comprising of a database, a web-based application supporting both direct data entry and file upload, a data download facility, and a report facility complying with all legal requirements. EDITH WP5 will also support EU Member States building, or adapting their national living donor registries by giving functional and technical advice. Finally, to govern the ELDR, a governance structure will be developed, data request procedures for ELDR requests shall be implemented, and recommendations for future sustainability of the ELDR will be made.

Transplant Recipient Registry - Work Package 6

WP6 will facilitate a consistent and comprehensive collection of data in EU Member States via national kidney follow-up registries and ultimately enable a European Kidney Transplant Registry. The main objective of this Work Package is therefore to support the establishment of a follow-up registry (FUR) of kidney transplant recipients in all EU Member States.

During the first year all existing national registries will be identified, and a basic data set (based on the data set developed in the previous EU project „European Framework for Evaluation of Organ Transplants” (EFRETOS)) will be defined. Subsequently during the second and third year of the EDITH project the FUR will be developed, tested and made available to EU Member States. The development of a ‘Quality of Life’ tool will be finalized and made available in the third year.

The combination of clinical data and information on the quality of life of transplant recipients will enable the evaluation of the benefits of transplantation in a more broad way thereby supporting the continuous enhancement of European transplant practice.