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The effect of differing kidney disease treatment modalities and organ donation and transplantation practices on health expenditure and patient outcomes

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ABSTRACT

The Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes (EDITH) aims to obtain information on long-term kidney transplant outcomes, long-term health outcomes of living kidney donors and detailed outcomes and costs related to the different treatment modalities of end-stage kidney disease. Nine partners from seven European Union countries will participate in this project.

Keywords: CKD, dialysis, kidney transplantation, quality of life, survival analysis

After the pioneering work in the 1940s and 1950s, renal replacement therapy (RRT) is now a permanent feature of the medical repertoire for the treatment of patients with end-stage kidney

disease (ESKD). As RRT is expensive, its costs impose a substantial burden on health care budgets. Moreover, as the prevalence of RRT keeps increasing (Figure 1), despite a stabilization in the number of patients starting this treatment in most European countries [1], a further increase in RRT costs is to be expected.

Even in the setting of developed countries, health care budgets are finite. For this reason, it is important to be informed on which RRT provides the best outcomes from a patient, a medical and a societal point of view. Although for >50 years the ERA-EDTA Registry has published data in Europe on both the survival of patients on dialysis and kidney grafts [2], there is insufficient information on:

- (i) Long-term transplant outcomes taking into account both donor and recipient information. This is not only alarming from a scientific perspective. It is also against

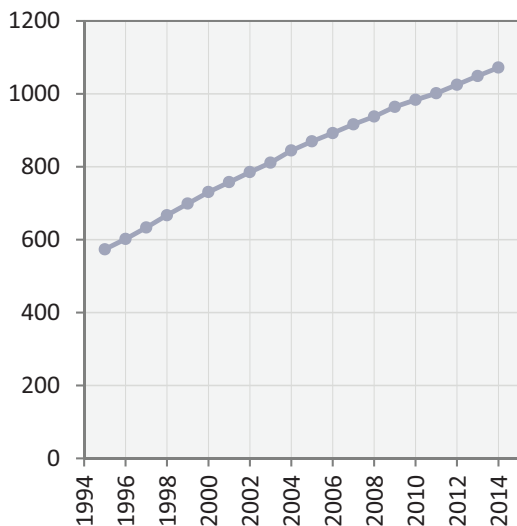


FIGURE 1: Increasing prevalence of RRT per million population in Europe.

the intention of Directive 2010/53/EU on standards of quality and safety of human organs intended for transplantation. After all, if potential risks related to donor characteristics are unknown, the best possible quality and safety of organ transplantation from these donors cannot be achieved and allocation of organs cannot make the best use of available donor organs.

- (ii) Long-term health outcomes of living kidney donors. Ensuring the highest possible protection for living kidney donors is also addressed in Directive 2010/53/EU. Two recent studies, a large one from the USA and a smaller one from Norway, have pointed at an increased risk of ESKD in living kidney donors [3, 4] and therefore have given rise to concern about the safety of living donor transplantation, even if the absolute risk of ESKD is suggested to be small. A European living kidney donor registry, to better quantify the risks related to living kidney donation, is therefore needed.
- (iii) Detailed outcomes and costs related to the different treatment modalities of ESKD.

This has led the European Union (EU) to organize a call to look at these issues and at the end of 2016 a grant was awarded to the Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes (EDITH) consortium led by the Deutsche Stiftung Organ Transplantation (DSO) in Germany. Within this consortium, 10 partners from all over Europe, together with collaborating stakeholders such as renal registries, the European Renal Association–European Dialysis and Transplant Association, the European Kidney Patients Federation, the European Kidney Health Alliance and various kidney foundations, will now work together to fill the existing gaps in knowledge as well as (to prepare the technical means) to collect the missing information. In doing this they will build on

their previous experience, including that gained in the former EU projects ACCORD and EFRETOS.

In the EDITH project, the ERA-EDTA Registry in the Academic Medical Center in Amsterdam together with the Italian National Transplant Centre will address the epidemiology and costs of different treatment modalities for ESKD. This includes an assessment of the frequency of the different treatment modalities for ESKD patients in different countries, of the factors influencing the choice of those treatment modalities by patients and doctors and of the impact of that choice on patient survival, quality of life and health care budgets.

The Dutch Transplant Foundation (DTF) together with the Biomedical Research Institute August Pi i Sunyer (IDIBAPS, Barcelona, Spain) will make the preparations for a European Living Donor Registry (ELDR) by identification of participating countries, description of a functional design and a governance structure for this registry, provision of functional and technical advice to national initiatives and setting up an ELDR that will allow long-term follow-up data collection from living donors.

Finally, a European follow-up registry for kidney transplant recipients will be prepared by the Eurotransplant International Foundation and the National Health Service Blood and Transplant (UK) in collaboration with DTF and IDIBAPS. Their task will include agreement on a data set to be collected, a description of the functional design of national follow-up registries, design of a web-based European transplant registry, including its governance structure, and carrying out a quality-of-life study among transplant recipients.

It is hoped that at the end of the EDITH project the partners will be able to make recommendations for harmonizing the availability of ESKD treatment across the EU and that the information generated by the project can be used for concrete action to improve the availability, quality and safety of kidney transplantation across EU member states.

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CONFLICT OF INTEREST STATEMENT

None declared. The results presented in this paper have not been published previously in whole or part, except in abstract format.

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