

# EDITH

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

## EDITH – WP5

European Living Donor Registry (ELDR)

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January 30, 2019

## Today's meeting

# WP 5 – European Living Donor Registry (ELDR)

### **Summary of objectives and activities**

### **Progress on the living donor registry**

- database, technical and functional design
- ELDR application development and testing
- adjusted time schedule 2019

### **Further issues regarding ELDR development**

# Summary of objectives and activities

## WP-5 objectives:

- 1) Development and implementation of a **European Living Donor Registry (ELDR)**
  - One common data set
  - One common data dictionary
  - According to recommended database structure
  - Governance organization & policies
  - Sustainable financial structure
  
- 2) *Provide advice to MS developing national systems to follow-up living kidney donors*

# WP5 project activities

1. Identification of participating countries
2. Setting up a European Living Donor Registry including long-term living donor follow-up data delivery to ELDR
3. Provide functional and technical advice to support national initiatives to set up or further develop living donor registries
4. Description of the governance structure of the ELDR
5. Proposal for achieving sustainability of the ELDR

# WP5 project activities

1. Identification of participating countries
2. Setting up a European Living Donor Registry including long-term living donor follow-up data delivery to ELDR
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4. Description of the governance structure of the ELDR
5. Proposal for achieving sustainability of the ELDR

# **A1. Identification of participating countries**

*M1-M9*

Development, distribution and analysis of a questionnaire

**D5.1:**

Report on outcomes of questionnaire about willingness to participate among EU Member States

**Milestone 1:**

Analysis of results of questionnaire about ELDR participation willingness among EU MS

## A2. Setting up an ELDR

*M3-M32*

Functional design, technical design and realization of ELDR database, application, report facility and analysis

**D5.2:**

Report on the ELDR specifications (dataset, functional and technical requirements)

**Milestone 3:**

Implemented ELDR database/application

**Milestone 4:**

Analysis of Living Donor follow-up data and experiences achieved with the ELDR

## **A3. Provide functional and technical advice to support countries**

*M9-M28*

Providing functional and/or technical help (helpdesk) for countries trying to start their own living donor registry

**D5.4:**

Report on support given during the course of the project to different national registries



# A4. Description of the governance structure of the ELDR

*M16-M30*

Description and implementation of (preferred) governance organization and data request procedure

**D5.3:**

Report on governance organization for the ELDR (and data request handling)

**Milestone 2:**

Installed governance organization

## **A5. Proposal for achieving sustainability of the ELDR**

*M25-M32*

Questionnaire among EU countries (especially WP5  
"participating countries")

### **D5.6:**

Recommendation report for a sustainable ELDR  
(including cost calculation and recommendations for  
future financing)

### **Milestone 5:**

Analysis of recommendations for a sustainable ELDR

# Updated time schedule

DELIVERABLE	PLANNED
D5.1 Report on outcomes of questionnaire (M9)	Completed Feb18 (M14)
D5.2 Report on the ELDR specifications (M12)	Delayed: Feb19 (M26)
D5.3 Report on governance organisation for the ELDR (M24)	Delayed: April19 (M28)
D5.4 Report on support given (M26)	Delayed: Oct19 (M34)
D5.5 Report on ELDR implementation (M30)	Delayed: Jan20 (M37)
D5.6 Recommendation report for a sustainable ELDR (M32 )	Delayed: Jan20 (M37)

# ELDR realization - details

ELDR REALIZATION	PLANNED FOR
Testing (& finalization) ELDR data entry	February19 ?
Testing (& finalization) ELDR upload, download (reports?)	March19 ?
Data entry/upload realization	Delayed: March19 (M28)
Sending letters to countries willing and able to participate; Offering help to countries that indicated to need help	March19
Donor data survey (reports?)	Delayed: June19 (M30)
Data entry	April19 →
Final report implementation	Delayed: Jan20 (M37)

# Dataset ELDR

4 parts:

- Donor demographic data
- Pre-donation data
- Peri- and post operative data
- Follow-up data

Changed:

- Mandatory items, no unknown-escape option  
->exception: File upload
- Free text fields: changed in LOV-field, or removal of field, or addition of several Y/N/U fields
- Peri- and post operative complications are combined

# Invitations to start ELDR registration

13 countries willing and able to participate

Invitation letter with the following information:

- Final dataset, with explanation on the changes
- Temporary governance document
- Request for user account information
- Time schedule ELDR implementation



# Offering help

10 countries that indicated to need help

Based on the kind of help needed IDIBAPS will send a letter or contact the specific contact persons

# Further ELDR development

## Suggested Reporting Facility

Implementation of a dashboard that includes the following reports:

- Number of donations performed per year (e.g. 2017-2018)
- Kaplan-Meier long-term donor survival, age-adjusted?
- Donor death within the first month, the first year
- Kaplan-Meier long-term freedom from renal replacement therapy
- Donor kidney function over time (pre-donation and at different time points)
- Percentage of donors with 5-year-function below 60 mL/min CKD-EPI
- Number of donors per country and year
- Donor age and age distribution



# Further ELDR development

## Citizen follow-up survey

**Option A: email survey**

**Option B: email + WhatsApp survey**

Dashboard Reporting facility and specifics of donor self reporting had not been budgeted in the original contract

# Questions

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