



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

Academic Medical Center (AMC), Amsterdam

Rianne de Jong

PhD student at EDITH project

Dr. Vianda S. Stel

Senior epidemiologist at ERA-EDTA Registry

Prof. Dr. Kitty J. Jager

ERA-EDTA Registry Managing Director

Work package 4: partners

Partners	Full name	Person month
01-DSO	Deutsche Stiftung Organtransplantation	0.54
02-OVSZ	Hungarian National Blood Transfusion Service	0.72
03-MoHRC	Ministry of Health - Republic of Croatia	0.54
04-AMC (<i>leading</i>)	AMC on behalf of European Renal Association – European Dialysis and Transplant Association (ERA-EDTA)	36.5
05-CNT-ISS (<i>leading</i>)	Istituto Superiore di Sanità - Centro Nazionale Trapianti	6.68
09-NHSBT	National Health Service Blood and Transplant	0.14

Work package 4: collaborating stakeholders

Institution	Contact person	City, country
ERA-EDTA	Prof. Ziad Massy	Paris, France
European Kidney Patients' Foundation	Mr. Mark Murphy	Dublin, Ireland
European Kidney Health Alliance	Sara Martin	Brussels, Belgium

Work package 4: collaborating stakeholders

Renal registries EU Member States

Contact person	Country
Johan De Meester	Belgium Dutch sp
Frederic Collart	Belgium French sp
James Heaf	Denmark
Mai Rosenberg	Estonia
Patrik Finne	Finland
Liliana Garneata	Romania
Jadranka Buturovic Ponikvar	Slovenia
Eduardo Martin Escobar	Spain
Maria Stendahl	Sweden

Renal registries Associated countries

Contact person	Country
Halima Resic	Bosnia Herzegovina
Olivera Stojceva-Taneva	FYR of Macedonia
Anders Asberg	Norway
Patrice Ambuhl	Switzerland

Aims work package 4

Academic Medical Center (AMC) = leading:

1. Assess **frequency** of different end-stage kidney disease treatment modalities

2. Investigate factors influencing the **choice** of treatment modalities **by patients and doctors**

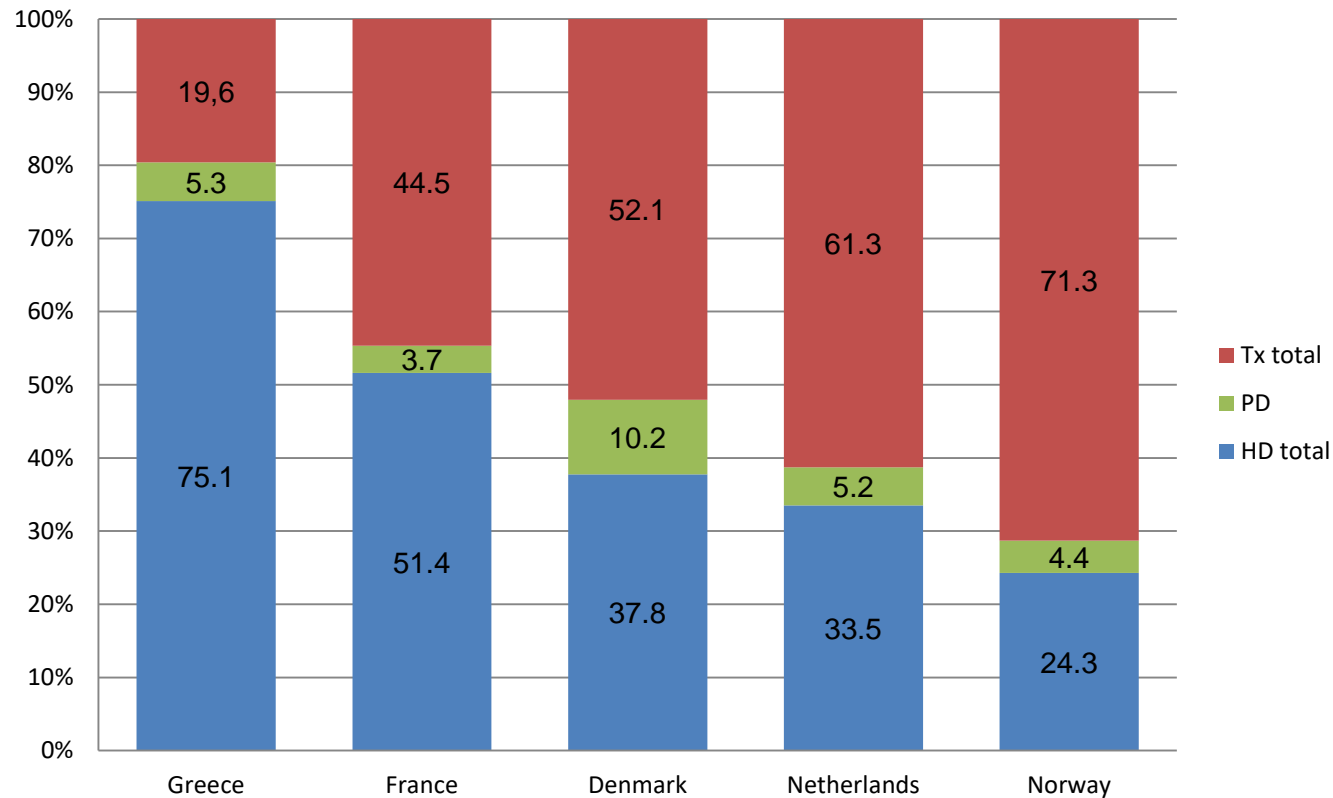
3. Assess **patient survival and quality of life** on different treatment modalities

Centro Nazionale Trapianti (CNT) is leading:

4. Investigate **costs** of different treatment modalities

RRT in Europe

Prevalent patients in 2015



PATIENT SURVEY

Patients' opinion on treatment modality choice

- Information provision
- Involvement in decision making
- Factors influencing choice
- Satisfaction with choice

In all EU Member States and associated countries



Patient survey

Development of
survey

March – Aug
2017

Pilot AMC
and abroad

Oct 2017

Translation

Oct-Nov
2017

Promotion &
distribution

6 months
(2017-2018)

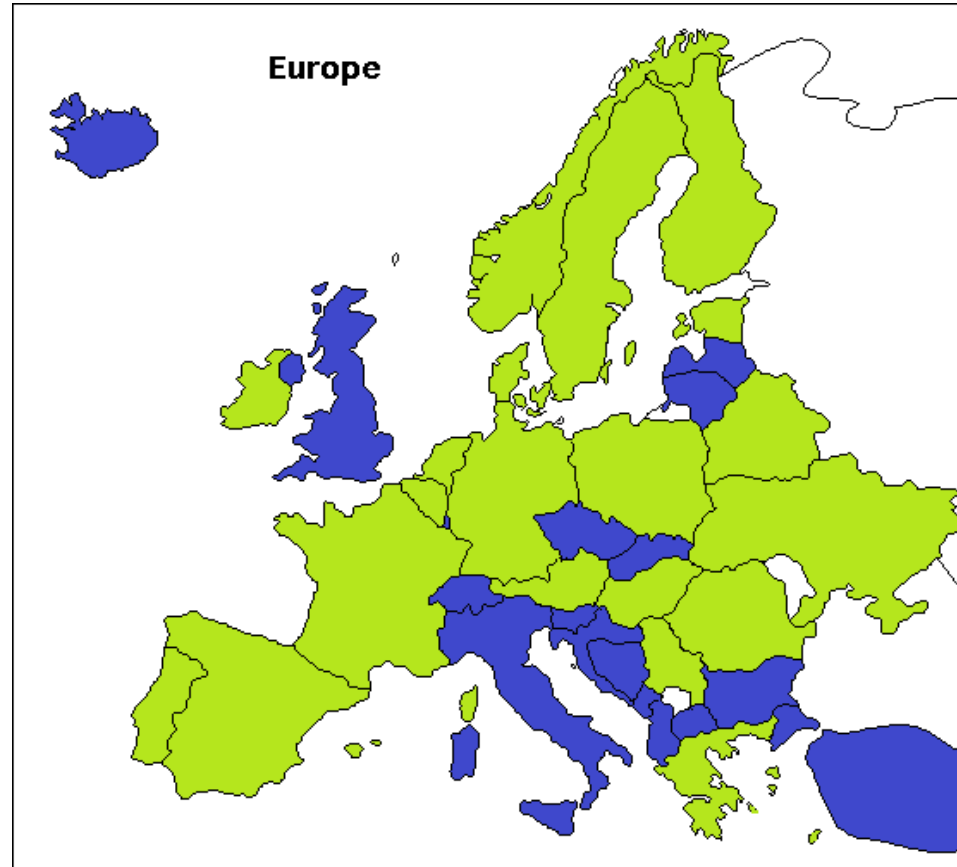
Promotion and distribution

Online questionnaire:

- Via patient associations (email)
 - Via nephrologists
 - Link on facebook/newsletters/websites
- 

Patient survey

- Participates
- In contact



NEPHROLOGIST SURVEY

- Contra-indications (medical, psychosocial, behavioural, logistic) for specific treatments and their importance
- Attitude towards different treatment modalities
- Barriers in providing most suitable treatment

Work in progress

For suggestions or questions:

Rianne de Jong
r.w.dejong@amc.nl

edith@amc.nl