EKHA
EUROPEAN KIDNEY HEALTH ALLIANCE

Vianda S. Stel

EDITH

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

The EDITH project

What is it and what do the first results show?

Vianda S. Stel

ERA-EDTA Registry
Academic Medical Center, Amsterdam

European Kidney Forum, 25 April 2018, Brussels

EDITH

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

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

3rd Health Programme of the European Union

1 January 2017 – 1 January 2020 (3 years)

DSO

NHS
Blood and Transplant

NEDERLANDSE TRANSPLANTATIE STICHTING

ORSZÁGOS
VÉRELLÁTÓ
SZOLGÁLAT

Ministarstvo
zdravlja
Za zdravlje. Zajedno.

IDIBAPS
Institut
D'Investigacions
Biomèdiques
August Pi i Sunyer

Eurotransplant

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EKPF
EUROPEAN KIDNEY
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agence de la
biomédecine

era
edta
REGISTRY

Aims per work package

WP4 Treatment modalities choices, outcomes and costs
for ESKD in the different EU Member States and associated countries

WP5 European Living Donor Registry (ELDR)
Supranational tool to share their data

WP6 Follow-up registry for kidney transplant patients
in all EU Member States

WP5

Wait for slide on results from WP5……..

WP 6: 24 of 28 countries replied on suggested dataset, 4 Member States have indicated the interest in a National registry, Quality of Life dataset to be defined

Donor data

NR referring to Efretos or New field nomination	Variable name	Definition
D1.1:NR	Donor ID	National ID code, same as used in the National or Regional registry that delivers the data.
D1.1:ER	Donor ER ID	ER ID code, could be the same as used in the National or Regional registry that delivers the data or determined by Consortium
D1.2	Donor Gender at birth	Donor's gender at birth
D1.3	Donor Blood Group	Donor's blood group
D1.4	Donor Height	Donor's body height
D1.5	Donor Weight	Donor's body weight
D1.6	Donor Age in Years at Organ Donation	Donor age in years at time of organ donation. For children under the age of two the value will be recorded with an exact first decimal. For all other ages it will be recorded with "0" as the first decimal.
D1.7	Donor Cause of Death	Two separate fields: one for coding system used and one for the respective death code
D1.8	Unified Cause of Death	For Liver and Intestine: ELTR, For Heart and Lung: ISHLT For Kidney And Pancreas: ICD-10.
D1.10	Donor Type	Type of donor
D1.11	Malignant tumours in the donor*	
D1.12 (D3.24)	Donor HLA - typing A-B-DR (1-2) antigen	Split in six variables: A1, A2, B1, B2, DR1, DR2
New and Tier 2 or 3 datafields that would be advisable to include		
New	Donor Past history of hypertension	Was the donor treated with anti hypertension drugs
New	Donor Creatinine at time of offer/retrieval	Ummol/l or mg/dl
D.2.2	Anti-CMV	IgG
D2.4	HIV (I/II)	Antibodies against Human Immunodificiency virus subtype 1 or 2
D2.8	HCV Ab*	Antibodies against hepatitis C virus
D3.33	Diabetes	Was the the donor diabetic?

Recipient data

NR referring to Efretos or New field nomination	Variable name	Definition
NEW:NR	Recipient ID	National ID code, same as used in the National or Regional registry that delivers the data.
NEW: ER	Recipient ER ID	ER ID code, could be the same as used in the National or Regional registry that delivers the data or determined by Consortium
R1.1	Patient's Gender at birth	Patient's Gender at birth
R1.2	Patient's ABO Blood Group	Patient's Blood Group Type
R1.3	Primary Diagnosis	All codings from national registries are stored: one variable describing which coding system(see derived variables) is used and one with the national coding.
R1.4: NR	Date of Birth	Date of birth of recipient
R1.4: ER	Recipient age at listing	Number of days between date of listing and date of birth
R1.5	Unified Primary Diagnosis	For liver and intestine: ELTR For heart and lung: ISHLT For kidney and pancreas: ICD-10
R1.7:NR	Listing Date	Date recipient was added to the waiting list. Can be entered separately for every transplant (first, second, etc
R1.7:ER	Age in years at listing	The age the recipient had reached at the time of listing for his first transplantation. For second and third transplantation, this variable is not entered.
D1.9 NR	Date the recipient went on dialysis for the first time, before his first transplantation. For second and third transplantations this variable is not entered	
R1.9:ER	Age in years at start of first dialysis	The age the recipient had reached being put on dialysis for the first time, before his first transplantation. For second and third transplantation, this variable is not entered.
New and Tier 2 or 3 datafields that would be advisable		
R2.1	HIV (I/II) Ab*	
R2.5	HCV Ab	
New	HBV	
New	CMV	
New	Dialysis type	The type of dialysis used
New	Sensitisation before first transplantation	

Transplantation Data

NR referring to Efretos or New field nomination	Variable name	Definition
T1.1:NR	Transplant Number ID	Local transplant number ID
T1.1:ER	Transplant ER Number ID	ER ID code, could be the same as used in the National or Regional registry that delivers the data or determined by Consortium
T1.2:NR	Transplant Date	
T1.2:ER	Age in years at transplant	the number of years between date of transplant and date of birth
T1.3	Country	Country where recipient is registered as recipient at time of transplant.
T1.4	Previous Transplants	Specification of previous transplant(s). For each of the previous transplants the specification will be required. PM: Intestine is currently NOT included
T1.7	Total Ischemic Time	Time elapsed between the time of clamping of the aorta and the time of declamping. For DCD: Time elapsed between circulatory arrest and the time of declamping.
T1.8	Organ Type	Since the entries on the registry will be on the transplant level, all organs and all possible combinations will be listed in this variable. PM: Intestine is currently NOT included. Multivisceral:
T1.12 (F1.3)	Date of Irreversible Graft Failure	
T1.13 (F1.4)	Primary Cause of Graft Failure. It does count when National Registry uses it.	Separate field for coding system used. All coding systems are allowed.
T1.14 (F1.5)	Unified Cause of Graft Failure	For Liver and Intestine: ELTR, For Heart and Lung: ISHLT For Kidney And Pancreas: ICD-10
T1.15 (F1.6)	Date of Death	
T1.16 (F1.7)	Cause of Death	All coding systems are allowed.
T1.17 (F1.8)	Unified Cause of Death	For Liver and Intestine: ELTR, For Heart and Lung: ISHLT For Kidney And Pancreas: ICD-10
T1.19 (T3.22)	Recipient's HLA - typing A-B-DR (1-2) antigen	Split in six variables: A1, A2, B1, B2, DR1, DR2
T2.11	Type of kidney transplant	
New and Tier 2 or 3 datafields that would be advisable		
New	Type of first previous transplant	
New	Type of second previous transplant	
New	Was the kidney transplanted part of a multi organ transplant	
New	In what kind of combination was the kidney transplanted	

Follow-up Data

NR referring to Efretos or New field nomination	Variable name	Definition
F1.1:NR	Recipient ID	National ID code
F1.1: ER	Recipient ER ID	ER ID code, could be the same as used in the National or Regional registry that delivers the data or determined by Consortium
New: NR	Date last seen	All measurements in this section are coupled to this date, except where noted otherwise.
New : ER	Number of days after transolant that therecipient was last seen	
F1.3	Number of days between transplant data and date of Irreversible graft failure	For Kidney and Pancreas: requirement of permanent replacement therapy or retransplantation. For Heart, Lung and Liver: Date of retransplantation or date of death. For Small Bowel: Date of graft removel retransplantation or date of death
F1.4	Primary Cause of Graft failure	Separate field for coding system used. All coding systems are allowed.
F1.5	Unified Cause of Graft Failure	For Liver and Intestine: ELTR For Heart and Lung: ISHLT For Kidney and Pancreas: ICD-10
F1.6:NR	Date of Death	
F1.6:ER	Number of days between date of transplant and date of death	
F1.7	Cause of Death	All coding systems are allowed
F1.8	Unified Cause of Death	For Liver and Intestine: ELTR For Heart and Lung: ISHLT For Kidney and Pancreas: ICD-10

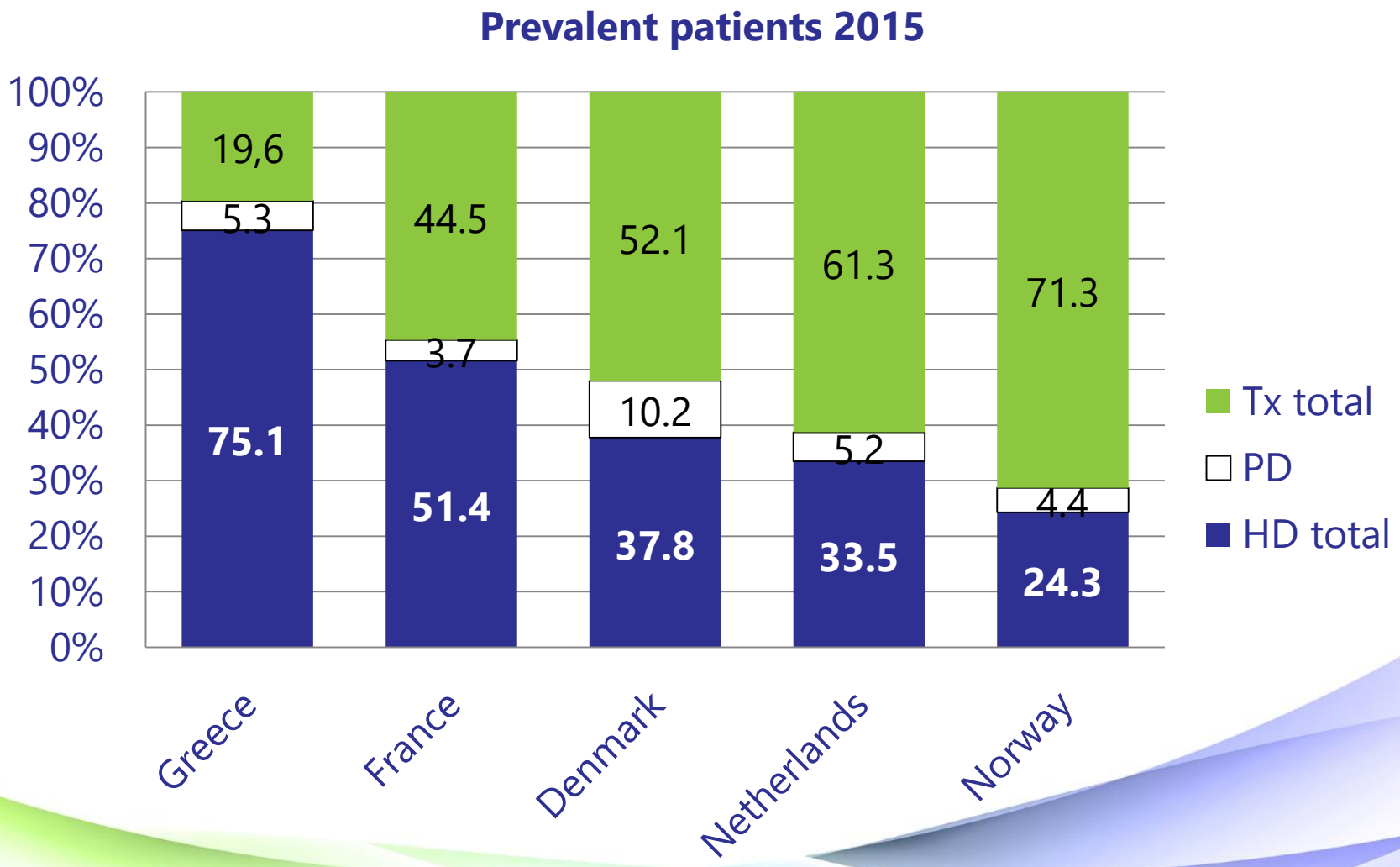
Eurotransplant

NHS Blood and Transplant

WP4: collaborating stakeholders

Institution	Contact person	City, country
European Kidney Health Alliance	Sara Martin	Brussels, Belgium
European Kidney Patients' Foundation	Mr. Mark Murphy	Dublin, Ireland
ERA-EDTA	Prof. Ziad Massy	Paris, France
Renal registries	Representatives	EU and non-EU member states

Large international differences



Why are there such large differences in prevalence of RRT modalities between European countries?

How about my salary?

Is he able to do home HD?

Can I get a transplant at my age?

I need somebody to help me with homeHD

I want good graft survival for my center

Should I follow his advice?

My last PD patient was 5 years ago…

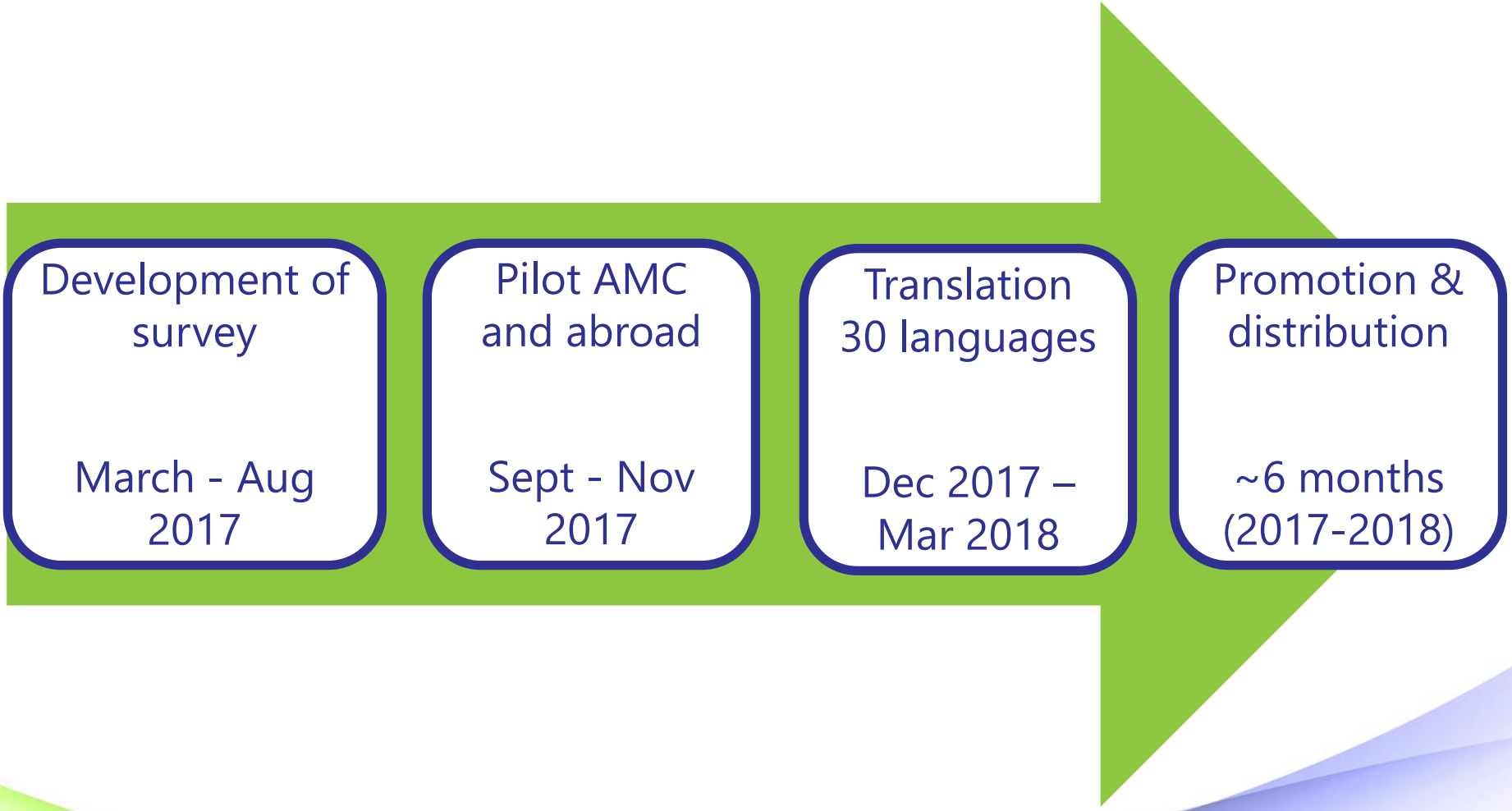
Can my wife donate a kidney to me?

EDITH Patient survey

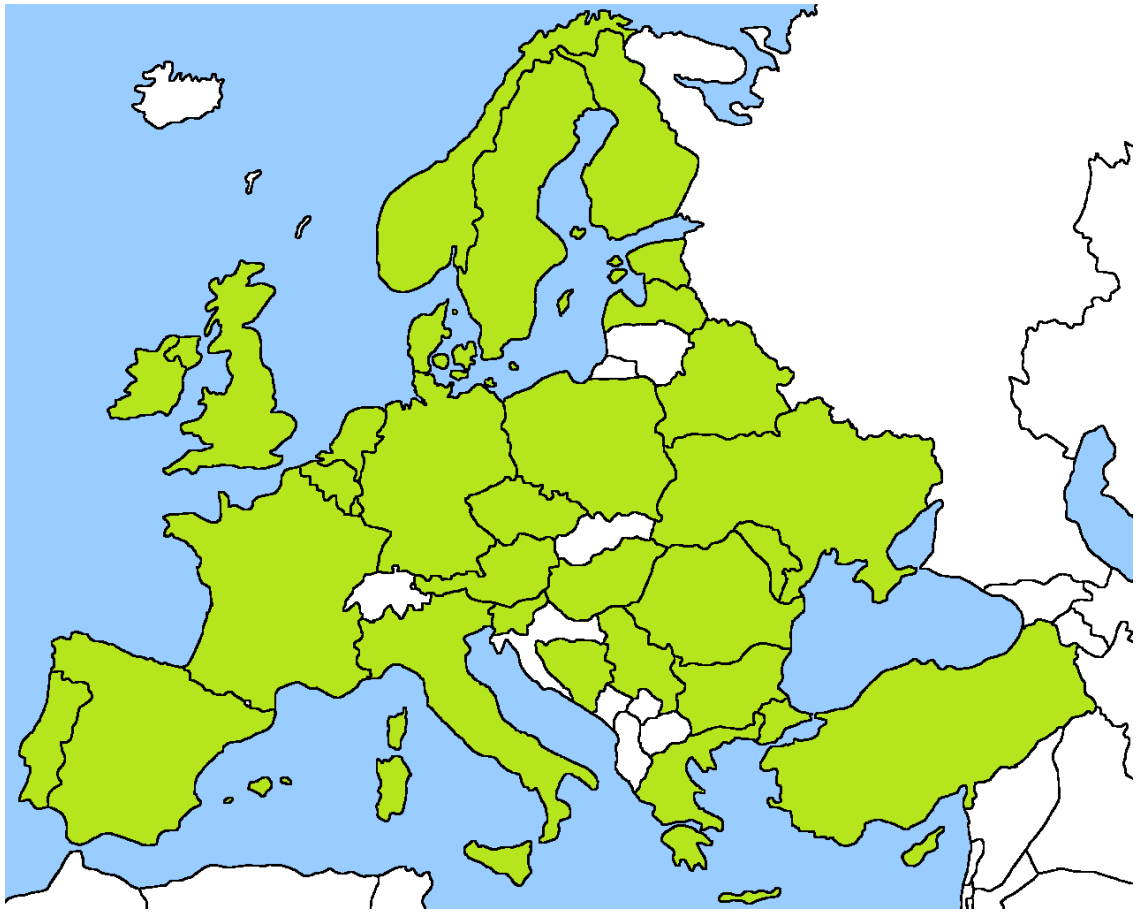
- Dialysis and kidney transplant patients' opinion on treatment modality choice
  - Information provision (also on conservative care)
  - Involvement in decision making
  - Factors influencing choice
  - Satisfaction with choice

In all EU Member States and associated countries

EDITH Patient survey



Participation in patient survey



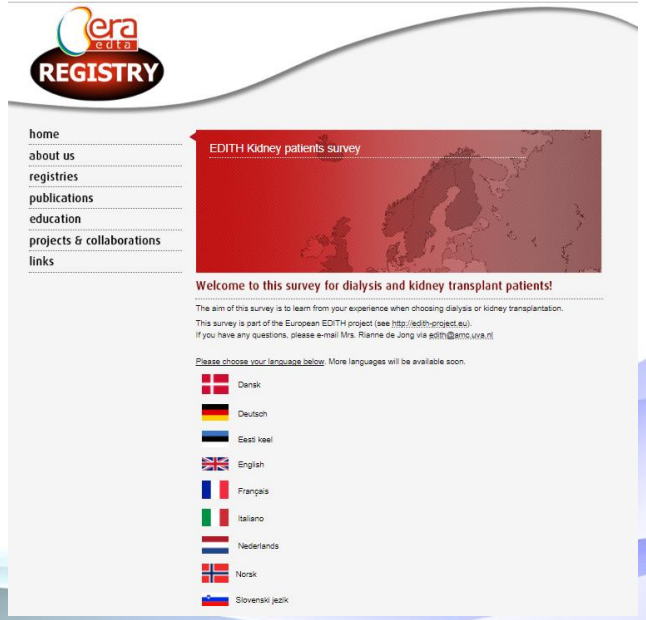
Promotion and distribution

Online questionnaire:

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

Links to patient questionnaire in different languages:

https://www.era-edta-reg.org



Available languages

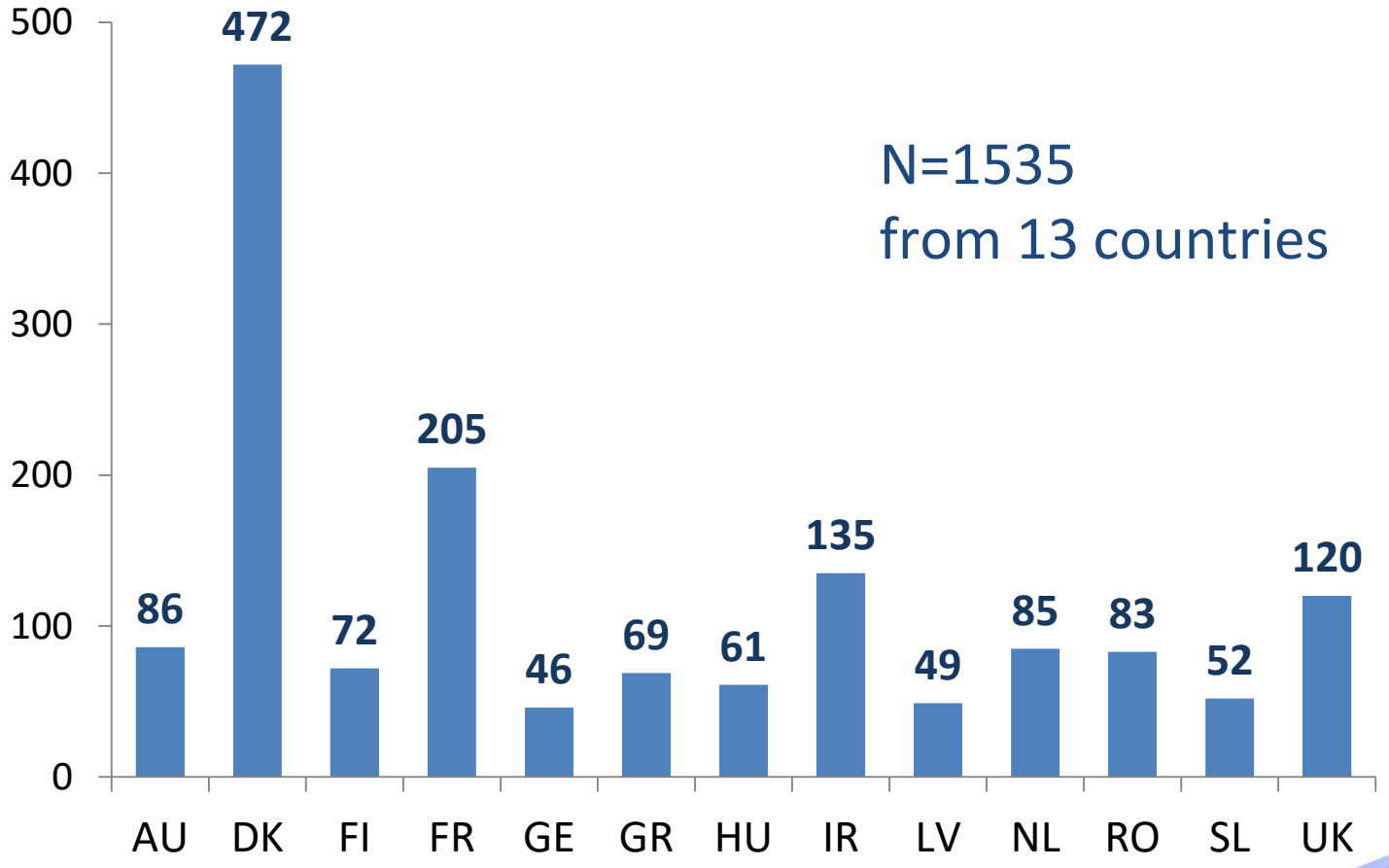
Currently available (N=20)

- Croatian
- Danish
- Dutch
- English
- Estonian
- Finnish
- French
- German
- Greek
- Hungarian
- Italian
- Latvian
- Macedonian
- Norwegian
- Polish
- Romanian
- Slovenian
- Spanish
- Swedish
- Turkish

Available soon (N=9)

- Bosnian
- Bulgarian
- Czech
- Icelandic
- Lithuanian
- Montenegrin
- Serbian
- Slovak
- Ukranian

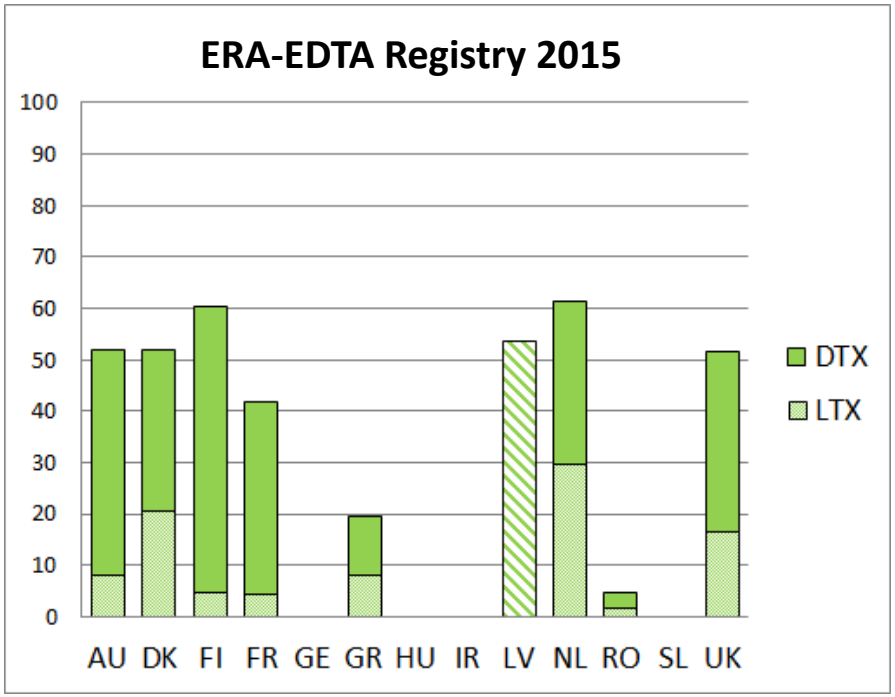
Patient numbers so far

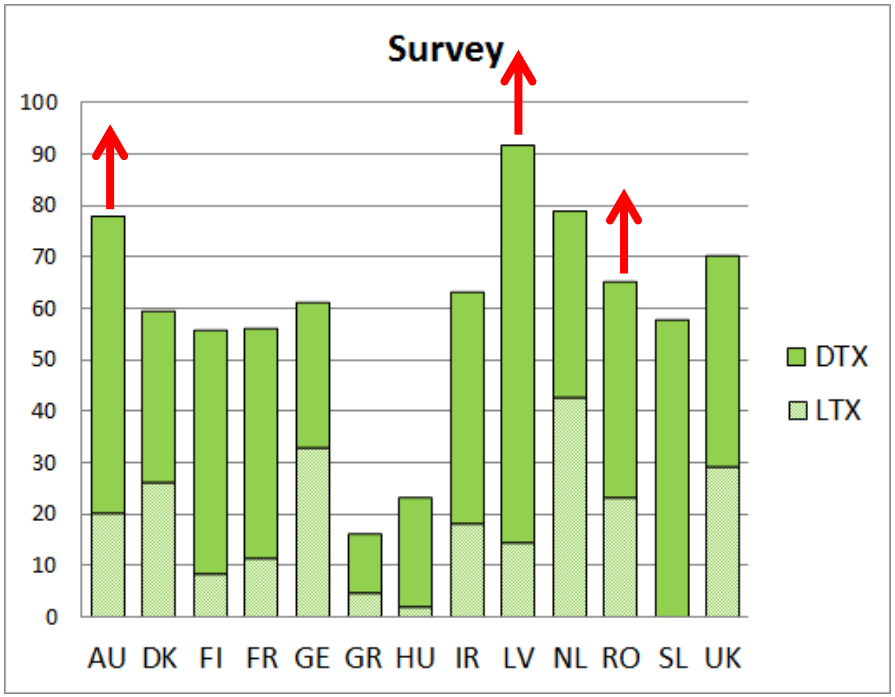


N=1535
from 13 countries

Preliminary results

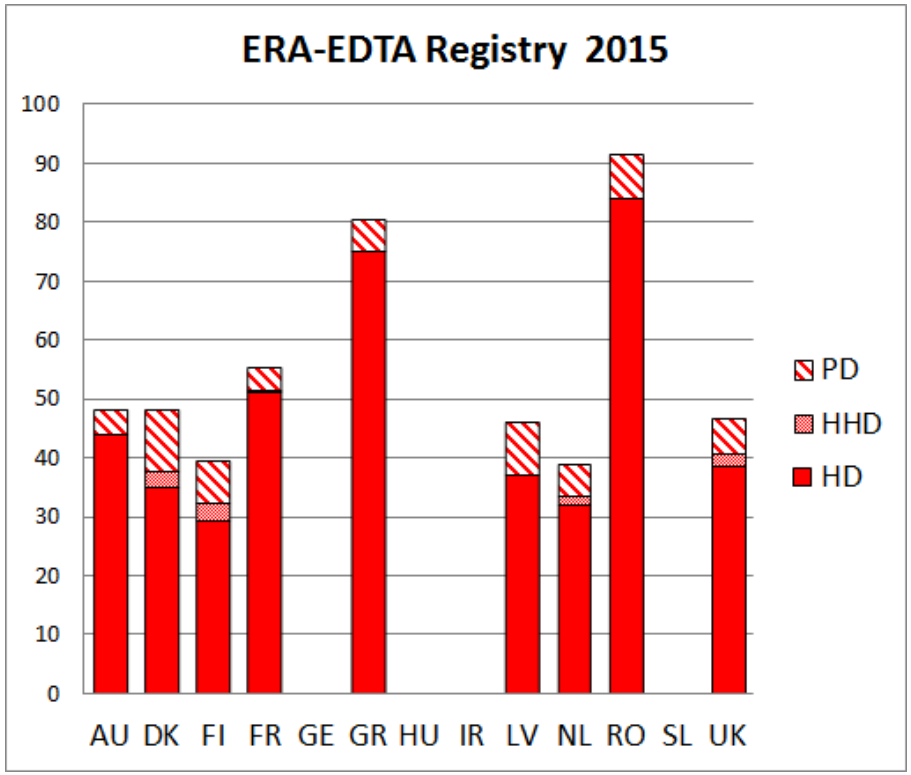
Percentage of transplant patients

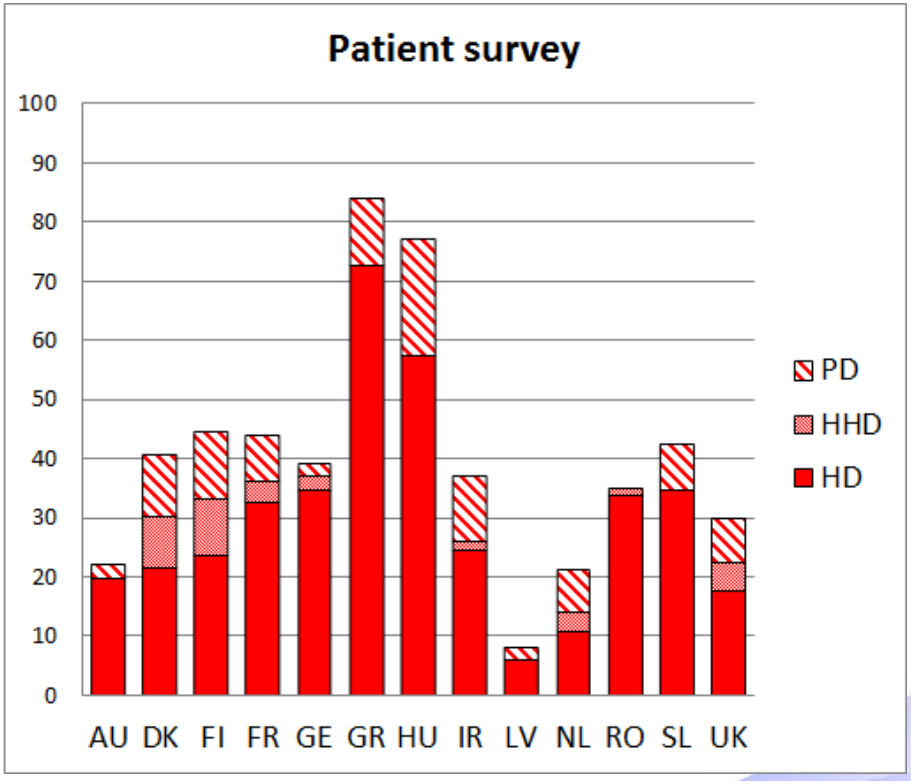




Preliminary results

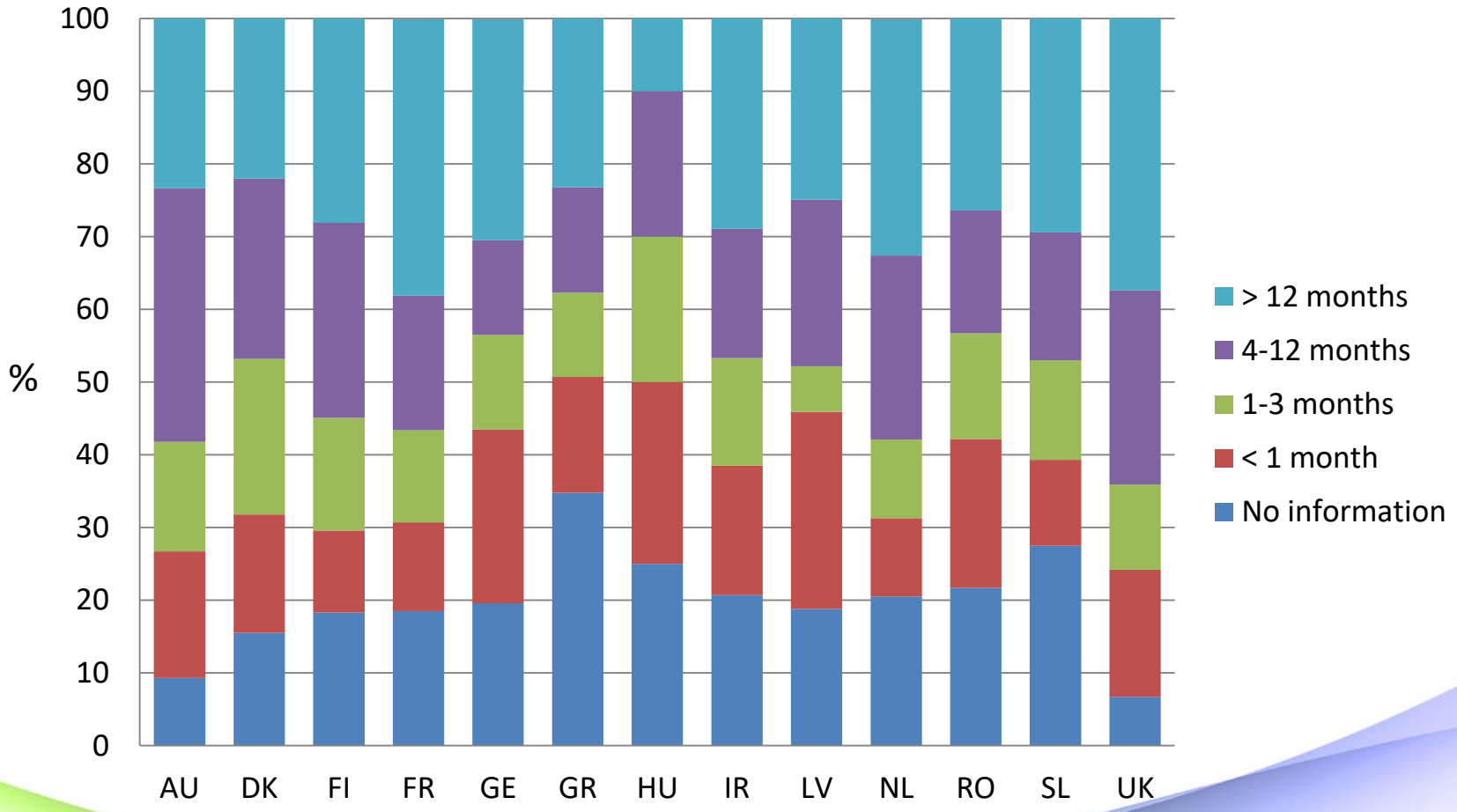
Percentage of dialysis patients





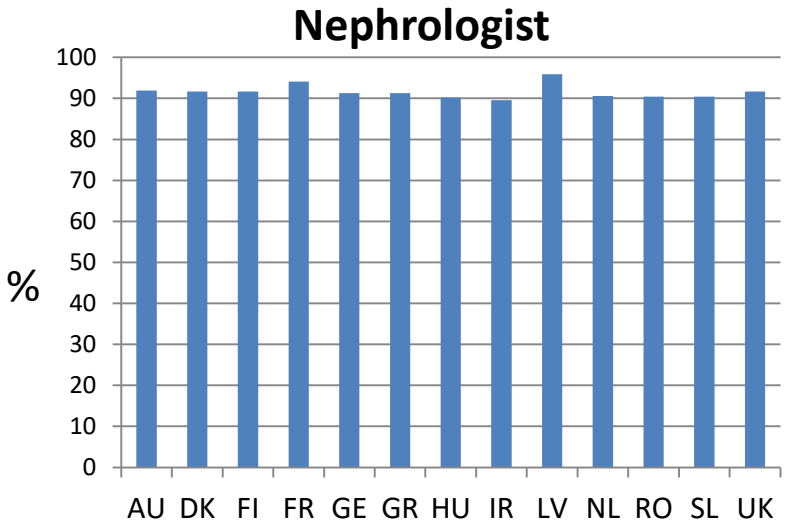
Preliminary results

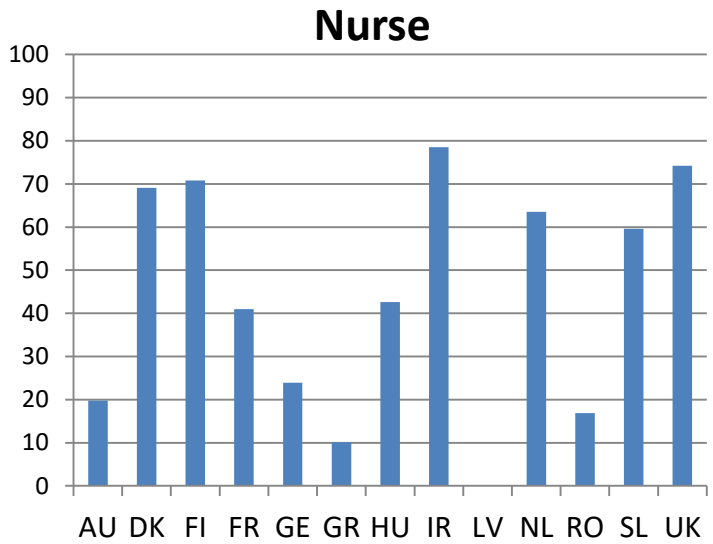
When did you receive information on modalities?

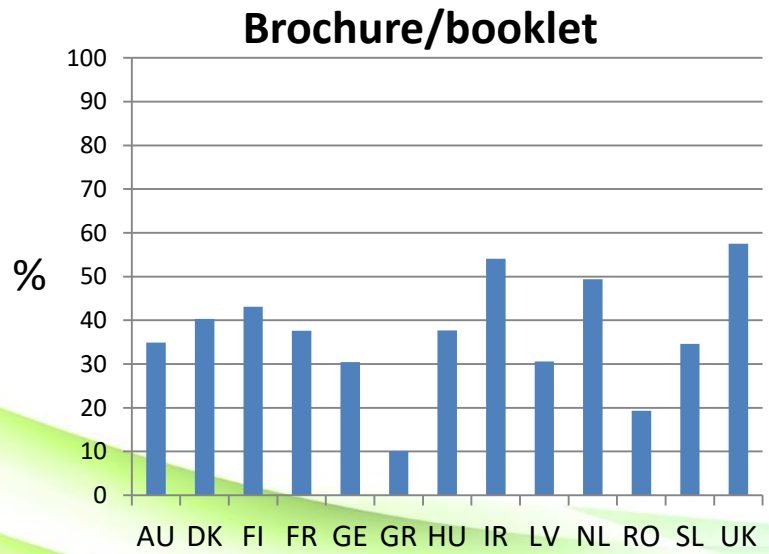


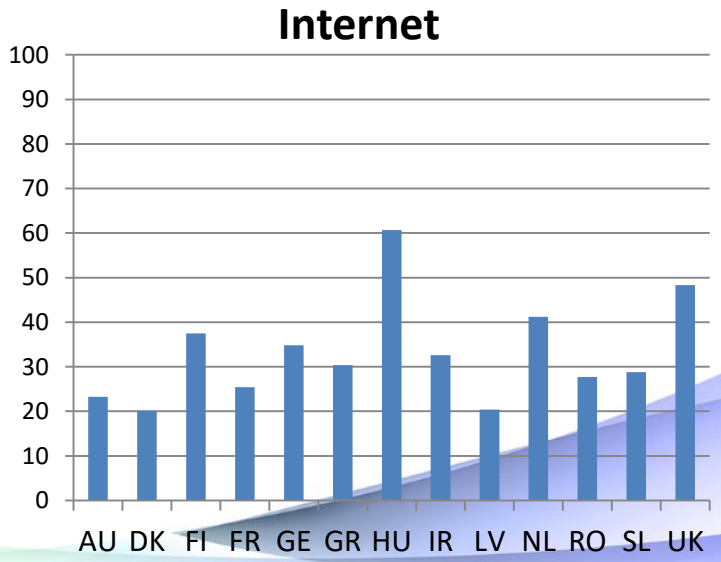
Preliminary results

Information source







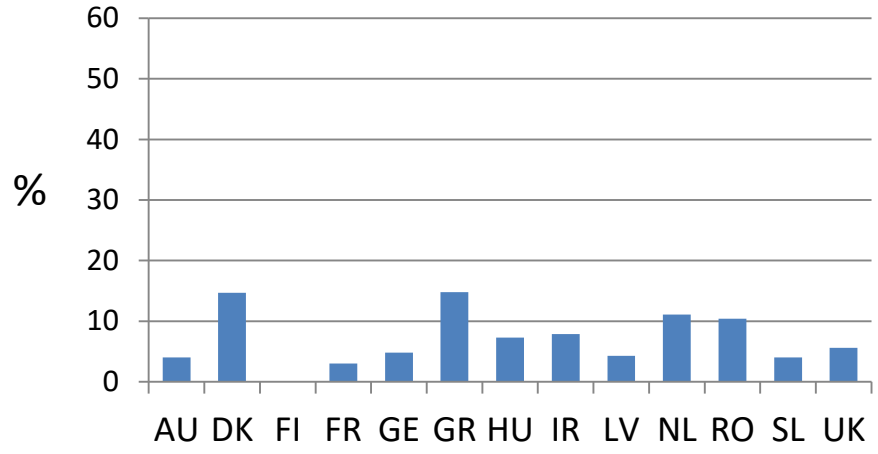


Preliminary results

No information on treatment modality

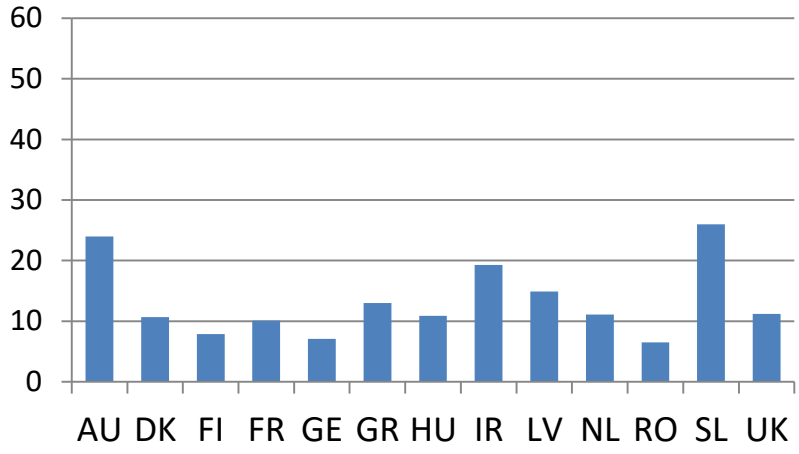
Deceased donor transplantation

patients <65 yrs, N = 1300



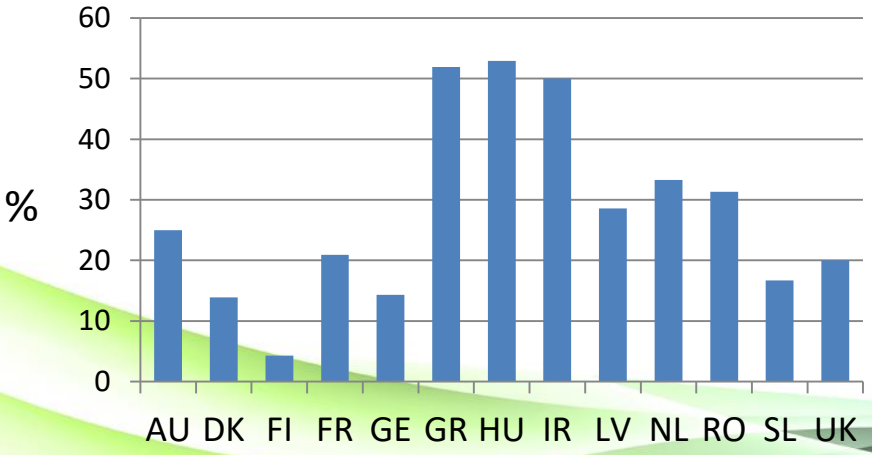
Living donor transplantation

patients <65 yrs, N=1300



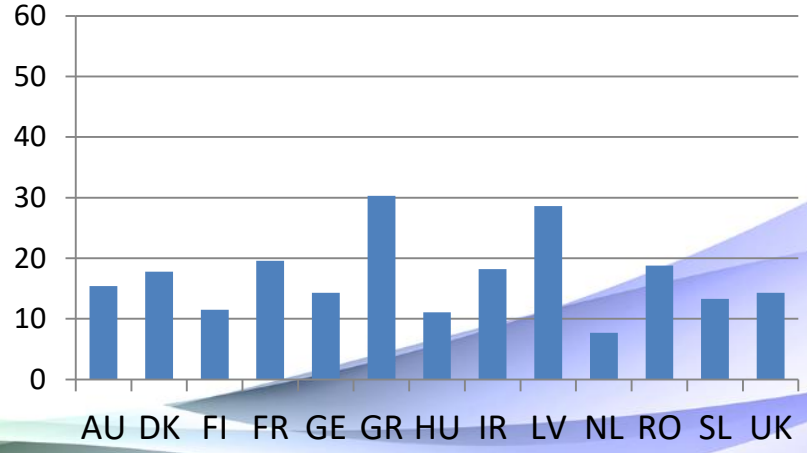
Home HD

dialysis patients <60 yrs, N=302



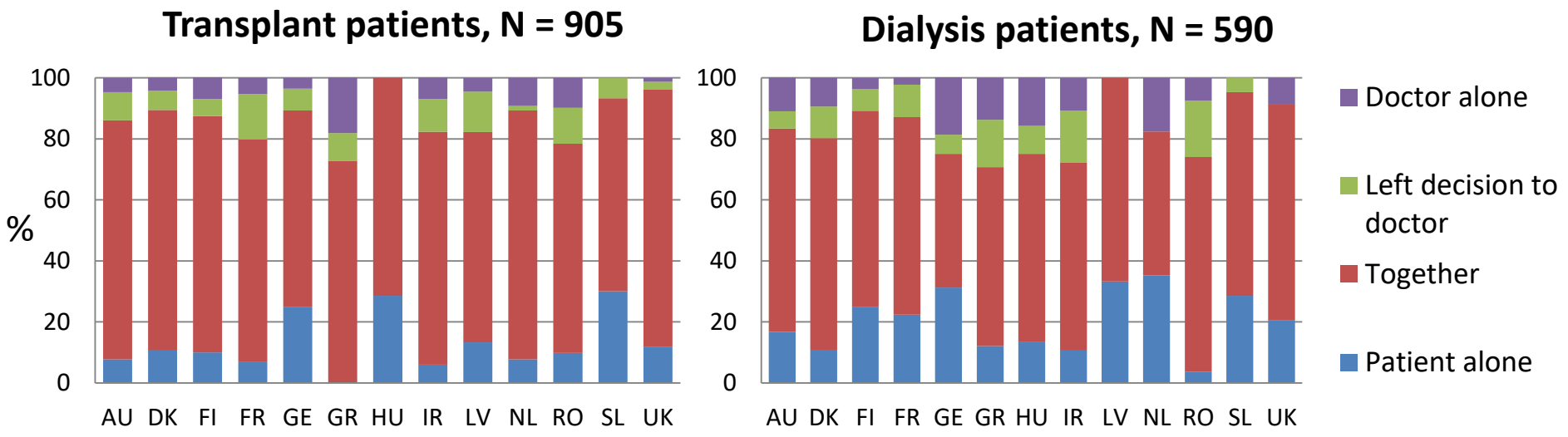
PD

dialysis patients <70 yrs, N=383



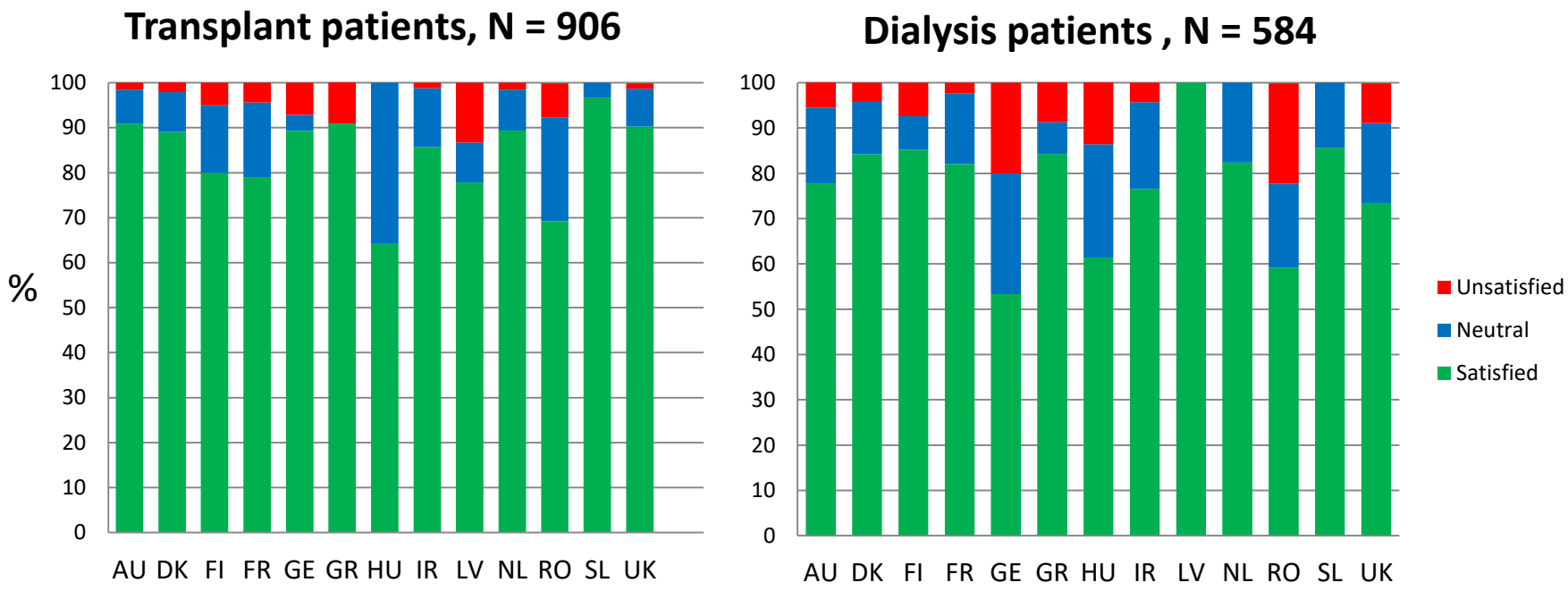
Preliminary results

How was the decision made?



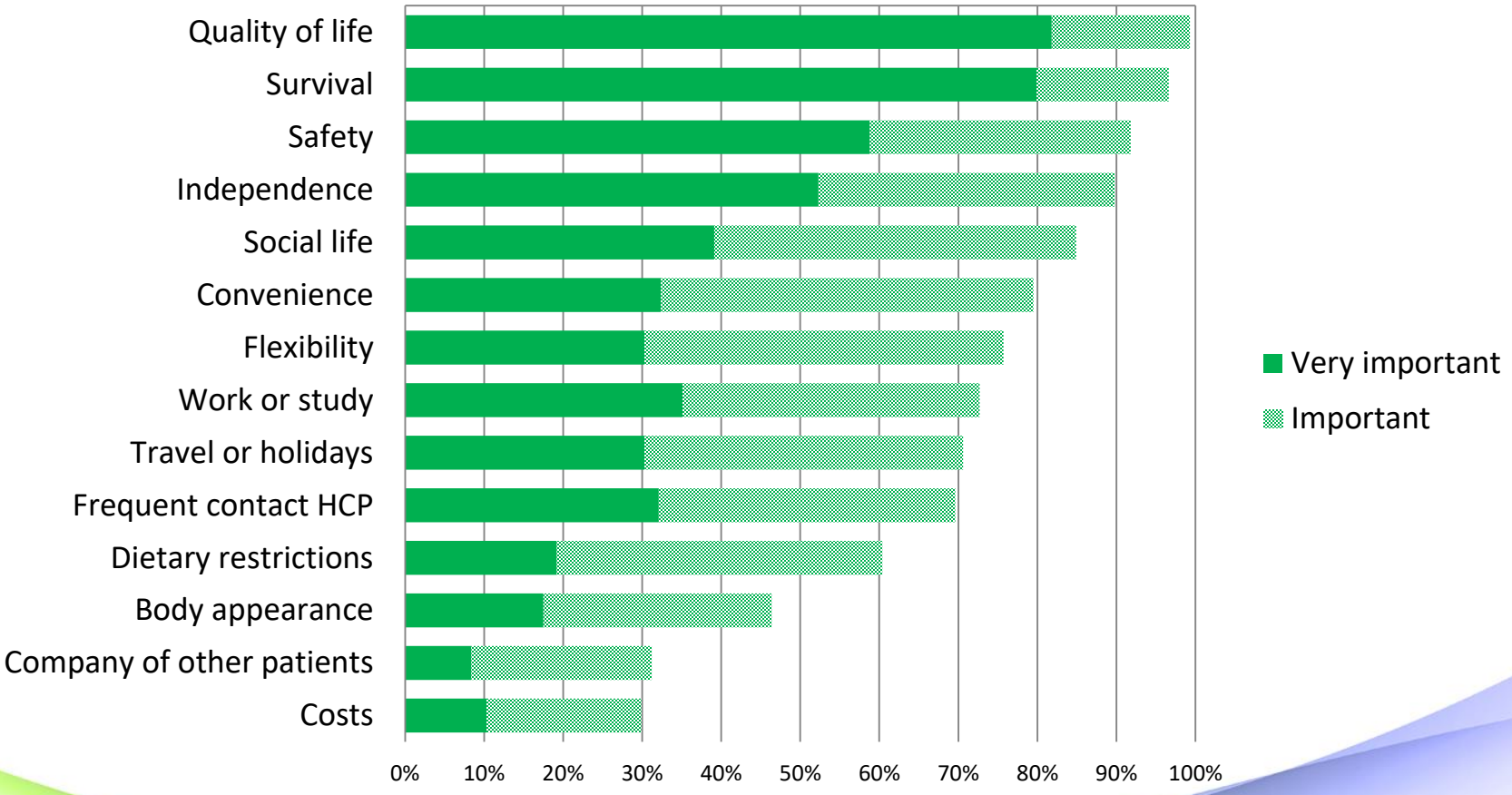
Preliminary results

Decision process satisfaction



Preliminary results

What is important when deciding about treatment modality?

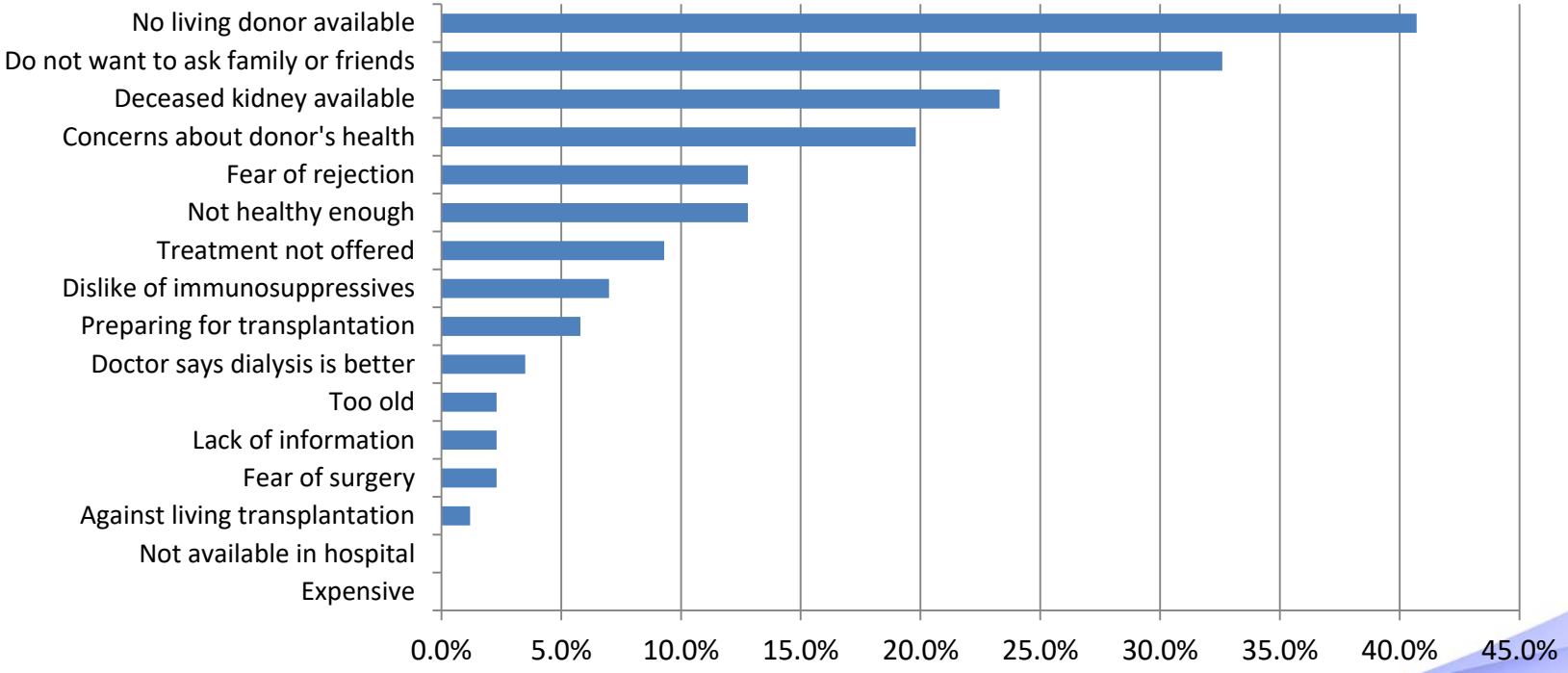


Preliminary results

Reasons: no kidney transplantation

No living donor kidney transplantation

patients ever on waiting list but no kidney transplant, N= 86



Preliminary results

Quotes: no kidney transplantation

- **“Transplantation is very rare in Greece unfortunately”** Male, Greece, 50’s
- **“Lack of organs”** Male, Romania, 40's
- **“I am not in favor of living donation”** Male, the Netherlands, 30’s
- **“Risk of kidney failure for my family members”** Female, France, 50's
- **“I'm afraid of the negative effects of immunosuppressive drugs”** Male, Slovenia, 40's
- **“My BMI is too high”** Female, Denmark, 50's

Conclusion

- The EDITH patient survey is in progress
- The EDITH project will
  - provide a better understanding of treatment choices made by patients and doctors to affect health care policies and
  - uncover differences between countries
- The EDITH project may help improving the access to
  - the most suitable dialysis modality and
  - kidney transplantation