



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

The EDITH project Update WP 4

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ERA-EDTA Registry
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EDITH meeting, January 30 2019, Leiden

Deliverables work package 4

1. Report on the frequency of different end-stage kidney disease treatment modalities (M30)

- HD, PD, Tx (ERA-EDTA Registry, Transplant Newsletter)
- Comprehensive conservative management (EDITH nephrologist survey)



Deliverables work package 4

2. Report on impact of treatment modality choice on health outcomes (M30)

- HD, PD, Tx
 - Patient and graft survival (ERA- EDTA Registry)
 - Quality of life (literature study)
- Comprehensive conservative management
 - Patient survival (literature study)



Deliverables work package 4

3. Report on factors influencing the choice of treatment modalities by patients and doctors (M32)
 - Literature review on barriers for RRT by patients
 - Systematic review on barriers for RRT provision by nephrologists
 - EDITH kidney patient survey
 - EDITH nephrologist survey

Deliverables work package 4

- Literature review on barriers for RRT by patients

Finished

- Literature review on barriers for RRT provision by nephrologists

Scientific paper sent to co-authors



EDITH kidney patient survey

Development of
survey

March - Aug
2017

Pilot AMC
and abroad

Sept - Nov
2017

Translation
30 languages

Dec 2017 –
May 2018

Promotion &
distribution

~6 months
(2017-2018)

EDITH kidney patient survey

Nov 2018

End of data collection

Feb 2019

Digitalization of 3000 paper versions
by two students

Feb-Jun 2019

Analyzing data and writing report

Some delay due to
- Amount of paper versions



EDITH nephrologist survey

Jan-Apr 2019

Data collection

May-Jun 2019

Analyzing data and writing the report

Some delay due to
- New GDPR

Still aiming to be on time.....



GDPR

Due to the new data protection legislation (GDPR)

the distribution of surveys in European countries is becoming much more difficult.

MEC waiver / approval

EDITH kidney patient survey + EDITH nephrologist survey

- Received a waiver from the MEC in Amsterdam UMC

Confirming that

- Not considered as medical research
- Approval by the MEC in Amsterdam UMC is not required

GDPR

During data collection it turned out that...

MEC approval from the UK was needed for the EDITH kidney patient survey, as this is considered medical research

As we did not ask for this approval:

We destroyed all data from the EDITH kidney patient survey from the UK (following the advice of our data protection officer)

GDPR

Having learned from this....

For the EDITH nephrologist survey:

- First ask if approval from the MEC in their country or centers is needed
- And if so, to ask for the possibility to receive such an approval within a 2 months period

Therefore, we may not be able to include all European countries

- Axel Rahmel and EU are informed about this
- Ad-hoc meeting registries and GDPR in Brussels (Feb 2019)

Next steps



Finalize the deliverables

1. Report on the different end-stage kidney disease treatment modalities (M30)
2. Report on impact of treatment modality choice on health outcomes (M30)
3. Report on factors influencing the choice of treatment modalities by patients and doctors (M32)

+ write scientific papers for PhD Rianne de Jong

Scientific paper

Nephrol Dial Transplant (2019) 1–8
doi: 10.1093/ndt/gfy390

ndt
Nephrology Dialysis Transplantation

How to increase kidney transplant activity throughout Europe— an advocacy review by the European Kidney Health Alliance

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Rianne W. de Jong² and Carmine Zoccali⁵

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Table 1. Kidney transplantation rate for different European countries

Country	No. of Tx pmp 2011	No. of Tx pmp 2016	% Tx of RRT 2011	% Tx of RRT 2016	% LTx 2011	% LTx 2016
Albania	3.9	5.9	26.1	17.3	100.0	88.2
Austria ^a	44.6	46.7	50.0	52.0	12.3	15.1
Belarus	18.2*	29.4	-	39.0	3.4*	4.2
Belgium ^b	41.8	39.5	41.6	42.6	7.8	10.0
Bosnia and Herzegovina	6.3	6.8	6.6	11.6	72.7	54.2
Bulgaria	2.3*	5.2	-	13.5	52.9*	29.7
Croatia	53.7	48.5	34.3	43.5	13.9	3.8
Cyprus	28.2*	22.2	-	-	61.3*	78.9
Czech Republic	31.9	44.6	-	40.2	12.0	10.0
Denmark	41.4	45.3	46.9	51.5	38.2	40.8
Estonia	32.8	31.9	56.7	56.7	6.8	9.5
Finland	32.7	47.5	59.0	60.5	7.4	8.4
France	46.3	54.1	44.3	44.9	10.1	15.9
Georgia	4.0*	7.0	-	9.3	100.0*	100.0
Germany	34.7*	26.0*	-	-	27.9*	28.5*
Greece	17.8	13.1	20.0	18.5	25.9	37.6
Hungary	25.1*	34.9*	-	-	18.7*	9.9*
Iceland	34.5	14.9	61.8	70.1	100.0	100.0
Ireland	42.7*	36.6*	-	-	14.1*	29.1*
Italy	28.8*	34.7*	-	-	12.1*	13.5*
Latvia	36.1	34.0	53.3	53.6	4.8	17.0
Lithuania	22.7*	37.7	-	37.9	4.0*	5.5
Luxembourg	-	-	-	-	-	-
Macedonia, former Yugoslav Republic	3.0	3.5	9.3	12.4	100.0	100.0
Malta	45.0*	50.0*	-	-	33.3*	25.0*
Moldova, Republic of	0.3*	5.4*	-	-	100.0*	36.4*
Montenegro	3.2	3.3*	46.5	-	0.0	100.0*
Norway	61.0	45.8	71.9	70.3	24.2	19.6
Poland	27.0	26.8	34.0	35.3	3.8	4.9
Portugal	50.2	49.5	36.7	36.4	8.9	12.7
Romania ^{c,d}	8.1	9.6	7.5	8.7	37.0	14.9
Russian Federation	6.8	7.5	21.2	19.2	18.4	21.4
Serbia ^{e,f}	15.6	7.4	14.0	9.5	38.9	36.5
Slovakia ^g	23.9	26.3	-	-	10.1	13.3
Slovenia	22.4	21.9*	30.0	-	0.0	4.3*
Spain ^h	52.9	64.4	49.9	52.4	12.5	11.4
Sweden	45.2	42.6	55.9	58.2	43.1	31.7
Switzerland ^{i,j}	36.6*	35.6	-	51.0	35.8*	39.3
The Netherlands	51.6	58.8	60.0	63.1	51.8	56.9
Turkey ^k	47.5	42.8	11.0	19.2	82.4	77.2
Ukraine ^l	1.4	3.1	13.1	14.6	58.1	74.0
UK ^{b,m,n,o}	43.7	45.3	48.9	54.0	37.5	28.7
All EU member states ^p	36.8	38.1	43.5	44.4	20.7	19.8
All non-EU member states	17.3	17.8	17.5	21.9	57.5	58.1

Table 4. Barriers to kidney transplantation experienced by patients with ESKD

Barriers	References
Fear of kidney rejection or graft failure	[24–28, 30]
Fear of surgery	[24–26, 31–34, 36]
Fear of medication (side effects, fear of infection)	[24–26]
Negative experiences (self or others)	[24–26, 35]
Distrust of health care professionals	[30, 33]
Doing well on dialysis	[25, 26, 30, 34, 36, 37]
Religious reasons opposing kidney transplantation	[25, 36]
Costs	[25, 28, 33, 34, 36–40]
<i>Only for living donors</i>	
Fear for donor’s health	[26–30, 39, 41–43]
Reluctance to ask potential living donors	[28, 29, 43]

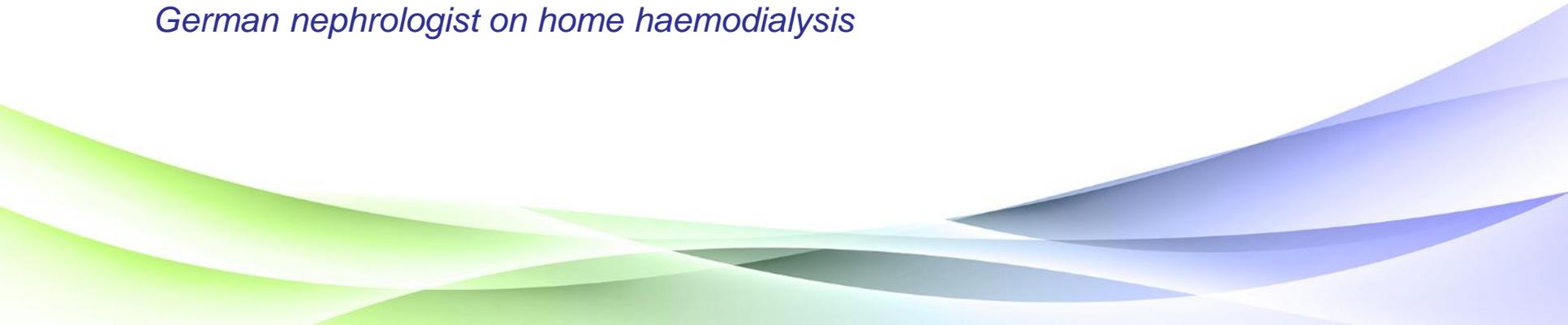
Systematic review

- Which **barriers** do nephrologists experience when providing the most suitable form of renal replacement therapy?
- 5 973 abstracts screened (2010-2018)
 - 6 qualitative + 10 quantitative articles included, on:
 - non conventional HD (n=2)
 - home HD (n=2)
 - PD (n=4)
 - PD and home HD (n=3)
 - kidney transplantation (n=2)
 - comprehensive conservative management (n=3)

Non-medical barriers to particular treatment modalities as experienced by nephrologists

	NCHD	home HD	PD	Tx	CCM
Barriers on the patient level					
Patient attitude and beliefs, lack of interest or motivation	x	x	x	x	
Lack of knowledge, limited health literacy			x	x	x
Sociocultural barriers (distrust, religion, language, poverty)		x	x	x	x
Patient fears		x		x	
Unsuitable living circumstances (home environment and distant location)		x	x		
Patient investment (costs, travel, time investment)	x	x	x	x	
Lack of support		x	x	x	x
Patient adherence and hygiene		x	x	x	
Barriers on the level of the healthcare professional					
Nephrologist attitude and beliefs, lack of interest or motivation	x	x	x	x	x
Lack of knowledge and lack of training	x	x	x		x
Nephrologist fears or concerns		x	x		x
Difficulty in selecting patients				x	x
External pressures				x	x
Problems with treatment discussion and education		x	x	x	x
Barriers on the level of the healthcare system					
Financial barriers	x	x	x	x	x
Lack of skilled staff	x	x	x	x	
Competition with other treatment modalities		x	x		
Organizational culture, coordination of care	x	x	x	x	x
Problems with logistics, infrastructure, equipment, supplies		x	x	x	
Lack of guidelines and prognostic tools, lack of evidence	x	x			x

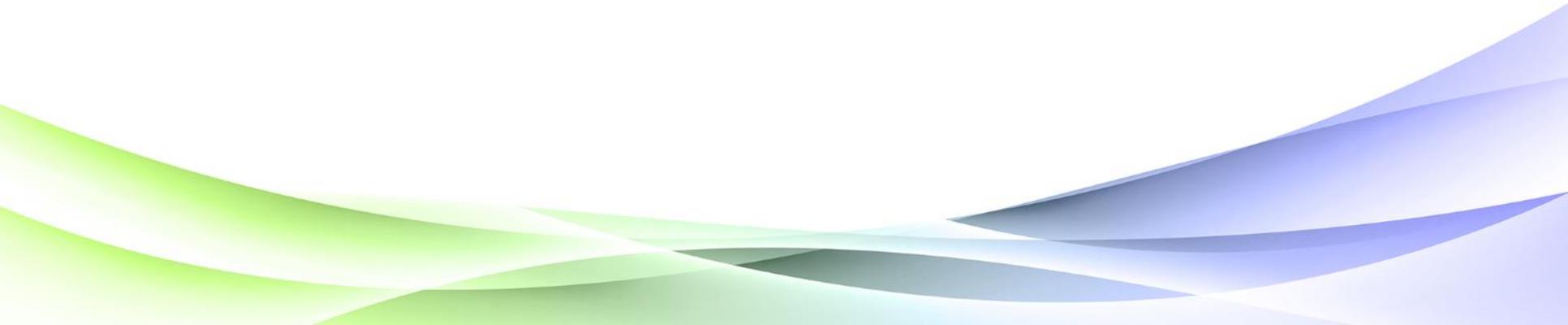
Quotes

- “Traditionally, everybody is linked to the doctors, everything connected with health is linked to the doctor so it’s difficult for the mind set to think about home [haemodialysis], being independent from the doctor. This is a tradition. It’s always a problem of mind set; it’s stronger in the south [of Italy].”
Italian nephrologist on home haemodialysis
 - “None [time spent on training about home therapies]. I very rarely get involved with PD peritonitis but that’s about it, nothing else and nothing on home haemodialysis.”
British nephrologist on home haemodialysis and peritoneal dialysis
 - “We have an in clinic environment more or less every 10 kilometres in capital cities and every 30 kilometres in rural areas...why should you buy additional equipment to comfort people to get treatment at home? ... there is just simply no need to do it at home ...”
German nephrologist on home haemodialysis
- 

EDITH kidney patient survey

- **Patients'** opinion on treatment modality choice
 - Information provision (also on comprehensive conservative management)
 - Involvement in decision making
 - Factors influencing choice
 - Satisfaction with choice

In all EU Member States and associated countries

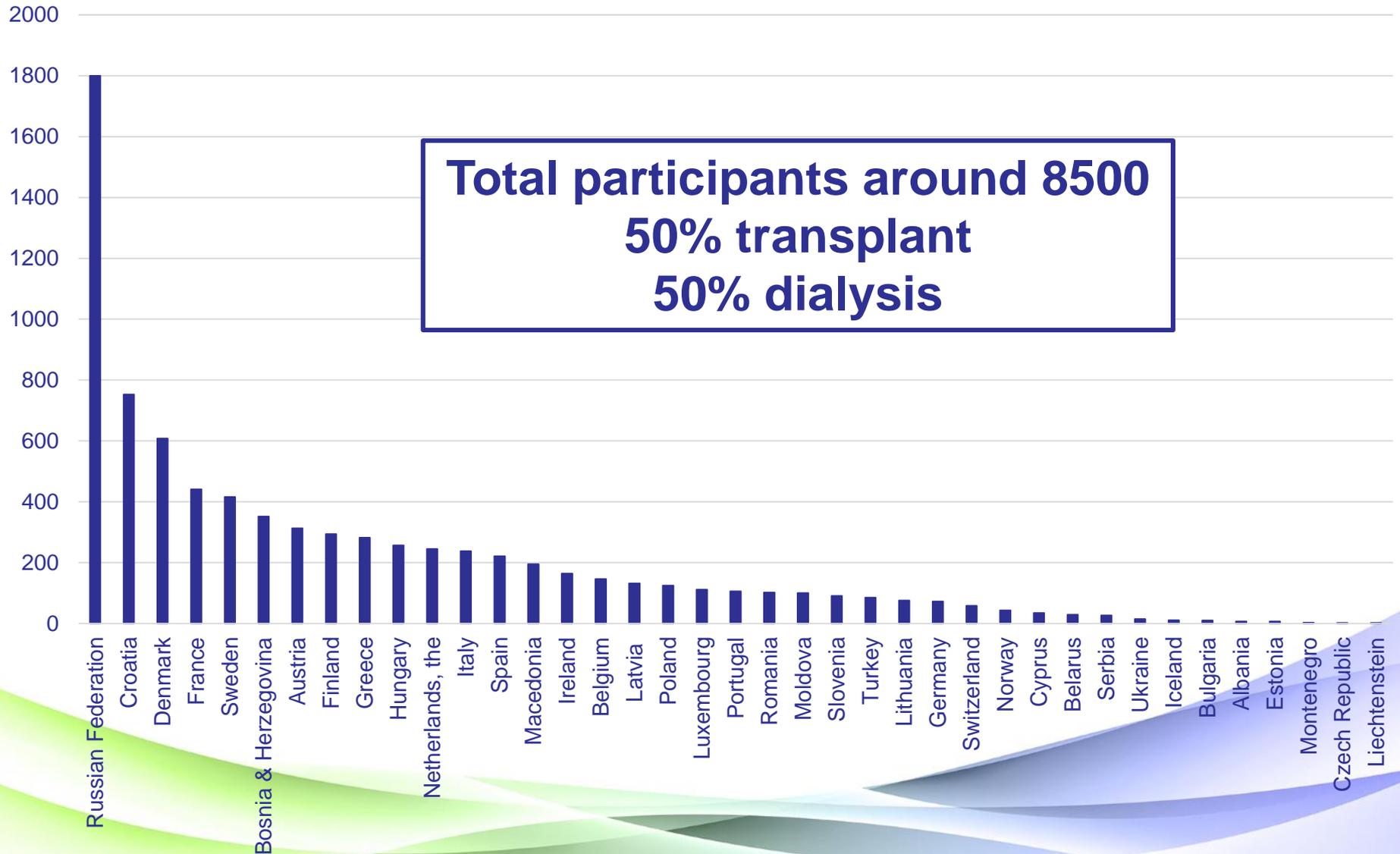


EDITH kidney patients survey



**>30 countries
participating**

EDITH kidney patients survey

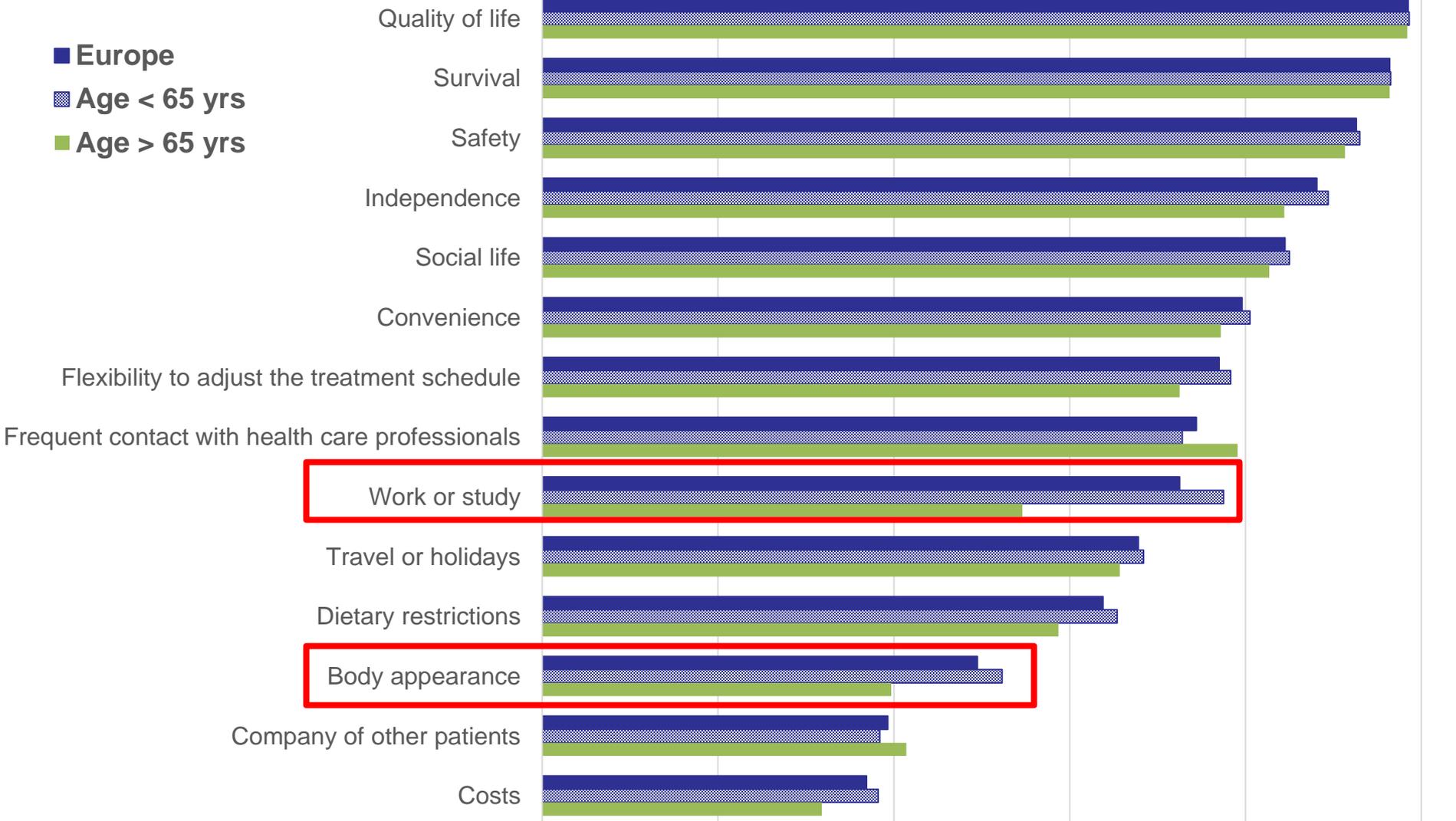


Europe total & age groups

Important when choosing RRT

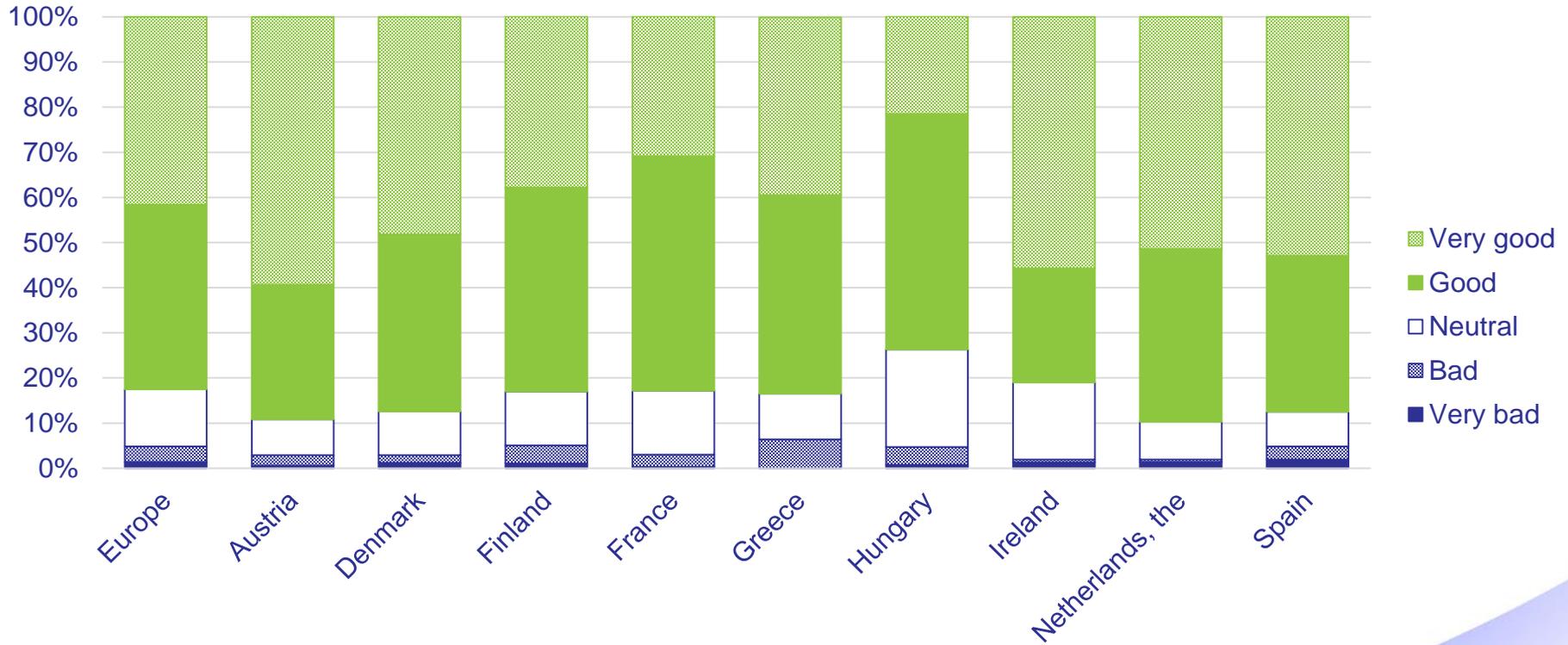
0% 20% 40% 60% 80% 100%

- Europe
- Age < 65 yrs
- Age > 65 yrs



Europe total & per country

Satisfaction with decision making



Countries with minimum of ??? respondents...

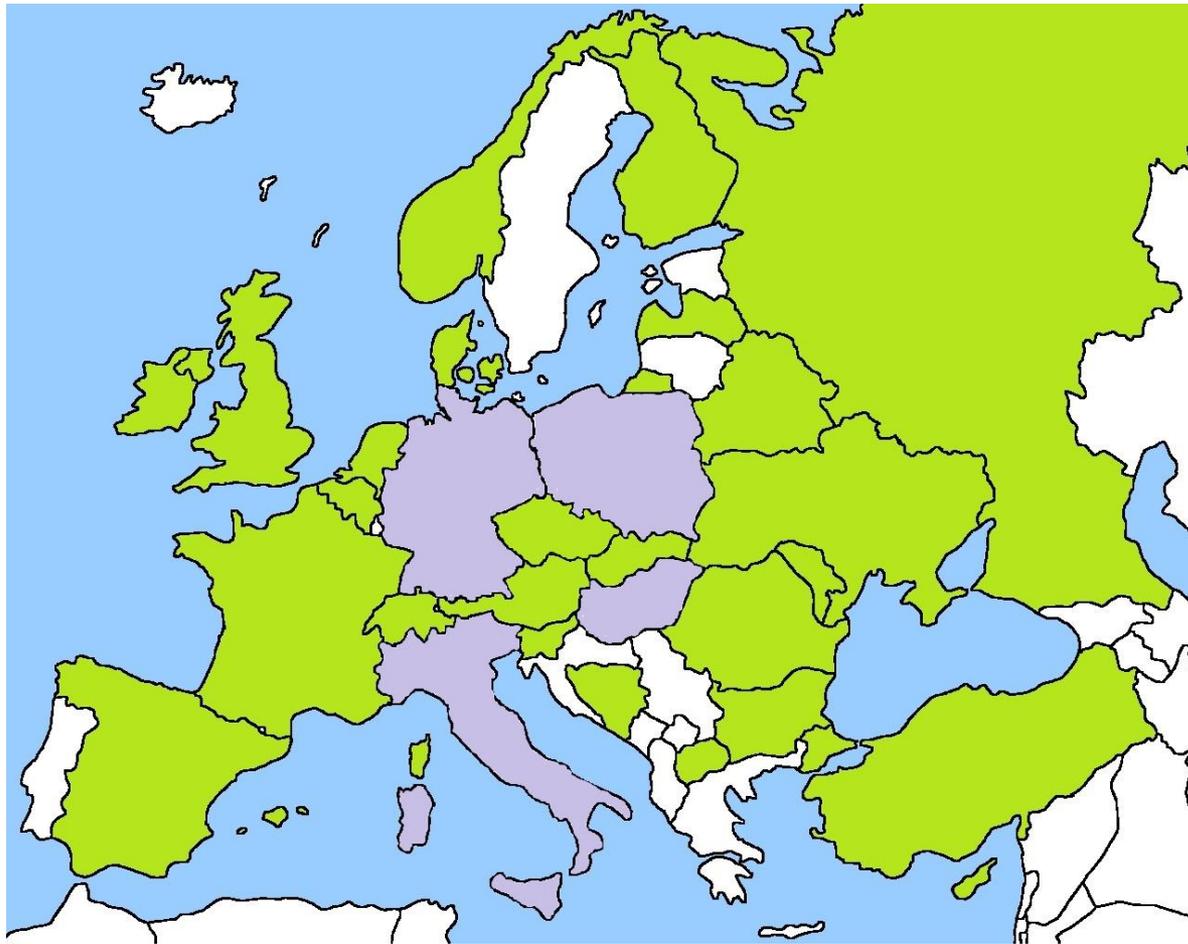
EDITH nephrologist survey

- **Nephrologists'** opinion on treatment modality choice
 - Information provision
 - Decision making
 - Barriers experienced when providing RRT
 - Initiatives to improve the uptake of certain forms of RRT
 - Remote patient management

In all EU Member States and associated countries

- Online
- In English
- 15 – 20 minutes to complete
- Promotion via National Societies, Registry contact persons, ERA-EDTA, ESOT

EDITH nephrologist survey



-  Ethical approval not needed
-  Ethical approval in progress

Acknowledgements

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Albanese	A Jaho	Macedonian	O Stojceva – Taneva, G Selim
Bosnian	H Resic, B Čengić-Roljic	Norwegian	K Lønning, M H Andersen
Bulgarian	R Vaklinova, H Nikolova	Polish	G Korejwo
Croatian	D Lazarin, S Živčić Ćosić	Portuguese	R Aguiar
Czech	I Rychlik, V Borcany	Romanian	L Garneata
Danish	J Goya Heaf, L Boesby	Russian	E Zakharova
Estonian	Ü Pechter, M Rosenberg	Serbian	M Zaric, S Bjelica, N Maksimovic
Finnish	A Cornér, R Muroma-Karttunen	Slovak	R Roland
French	Z Massy, C Couchoud,	Slovenian	M Malgaj, J Buturovic-Ponikvar
German	S Venhaus, F Schaub, A Rahmel, M Lingemann	Spanish	M Collado
Greek	G Marangou d' Avernas, E Groutidou Petridou, M Sekadakias	Swedish	M Stendahl, H Rydell
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