

On patient choice and education: results of an European questionnaire in 9 European countries

R. Vanholder, University Hospital,
Ghent, Belgium

What are the factors to be considered when studying health inequalities in kidney care in Europe?

Multi-Country Survey of Patient Choice of RRT in Europe

- Goal: to explore and address the patient choice of treatment (or lack thereof) in select Member States and address how it relates in the context of **sustainability** of kidney care, **economic impact** on health systems, and **outcomes** impact on the patient and his or her **quality** of life.

Which factors should we take into account?

A decorative graphic at the bottom of the slide consisting of several overlapping, semi-transparent blue waves or curves that create a sense of movement and depth.

Which factors should we take into account?

- The highest survival and quality of life is offered by transplantation followed by home dialysis strategies (PD and home HD)

Which factors should we take into account?

- The highest survival and quality of life is offered by transplantation followed by home dialysis strategies (PD and home HD)
- Among dialysis strategies, patients preference goes towards home strategies, irrespective of whether they are treated in center or not

Which factors should we take into account?

- The highest survival and quality of life is offered by transplantation followed by home dialysis strategies (PD and home HD)
- Among dialysis strategies, patients preference goes towards home strategies, irrespective of whether they are treated in center or not
- TP and Home strategies are more cost-effective to societies

Survey Methodology



Survey Methodology

- 9 countries in various regions of Europe were recruited
 - UK
 - France
 - Netherlands
 - Slovenia
 - Lithuania
 - Spain
 - Greece
 - Portugal (too few responses to use in comparisons – launched again and still running)
 - Poland (still running)

Survey Methodology

- 9 countries in various regions of Europe were recruited
 - UK
 - France
 - Netherlands
 - Slovenia
 - Lithuania
 - Spain
 - Greece
 - Portugal (too few responses to use in comparisons)
- 1 survey of patients and 1 survey for health care professionals to compare and contrast

Survey Methodology

- 9 countries in various regions of Europe were recruited
 - UK
 - France
 - Netherlands
 - Slovenia
 - Lithuania
 - Spain
 - Greece
 - Portugal (too few responses to use in comparisons)
- 1 survey of patients and 1 survey for health care professionals to compare and contrast
- Survey translated in local languages (2 per country x 8 = 16 surveys)

Survey Methodology

- 9 countries in various regions of Europe were recruited
 - UK
 - France
 - Netherlands
 - Slovenia
 - Lithuania
 - Spain
 - Greece
 - Portugal (data still under analysis)
 - Poland (data still under analysis)
- 1 survey of patients and 1 survey for health care professionals to compare and contrast
- Survey translated in local languages (2 per country x 8 = 16 surveys)
- Conducted online: Survey Monkey

Survey Methodology

- 8 countries in various regions of Europe were recruited

- U
- Fr
- Ne
- Sl
- Li
- Sp
- Gr
- Po



Grant Agreement number:
PP-1-2015

professionals to

} = 16

- 1 sur
- comp

- Surve
- surve



<http://www.edith-project.eu>

- Conducted online: Survey Monkey
- Survey deployed via EKHA's member networks (national patient, national nurse, and national physician societies)

RISK OF BIAS



- Participant bias of patients/professionals who have internet access and are web savvy, and have time and interest in giving a response

RISK OF BIAS



- Participant bias of patients/professionals who have internet access and are web savvy, and have time and interest in giving a response
- Because of time restrictions, we can only offer the results of the comparison country by country

PARTICIPATION



COUNTRY	PATIENTS	PROFESSION.
Spain	163	120
France	78	55
UK	110	75
Greece	136	101
Lithuania	52	35
Slovenia	28	16
Netherlands	95	49
Portugal	0	9

PARTICIPATION

COUNTRY	PATIENTS	PROFESSION.	INHABITANTS
Spain	163	120	46
France	78	55	64
UK	110	75	65
Greece	136	101	11
Lithuania	52	35	3
Slovenia	28	16	2
Netherlands	95	49	17
Portugal	0	9	

PARTICIPATION

COUNTRY	PATIENTS	PROFESSION.	INHABITANTS
Spain	163	120	46
France	78	55	64
UK	110	75	65
Greece	136	101	11
Lithuania	52	35	3
Slovenia	28	16	2
Netherlands	95	49	17
Portugal	0	9	
Total	662	460	

PARTICIPATION



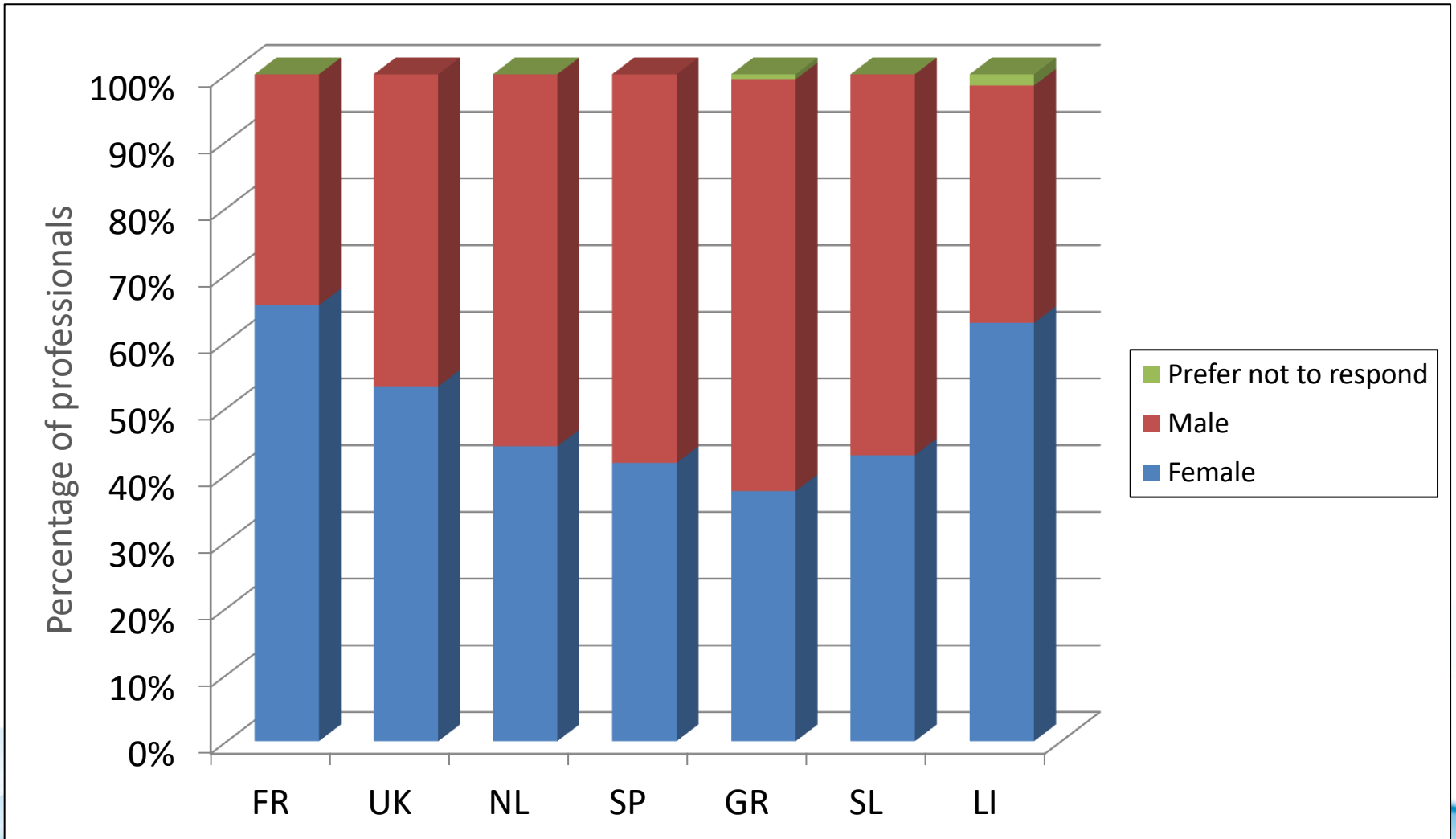
COUNTRY	PATIENTS	PROFESSION.	INHABITANTS	% TP	% PD
Spain	163	120	46	52	13
France	78	55	64	44	7
UK	110	75	65	53	14
Greece	136	101	11	20	6
Lithuania	52	35	3	32	3
Slovenia	28	16	2	33	4
Netherlands	95	49	17	59	15
Portugal	0	9			

PARTICIPATION

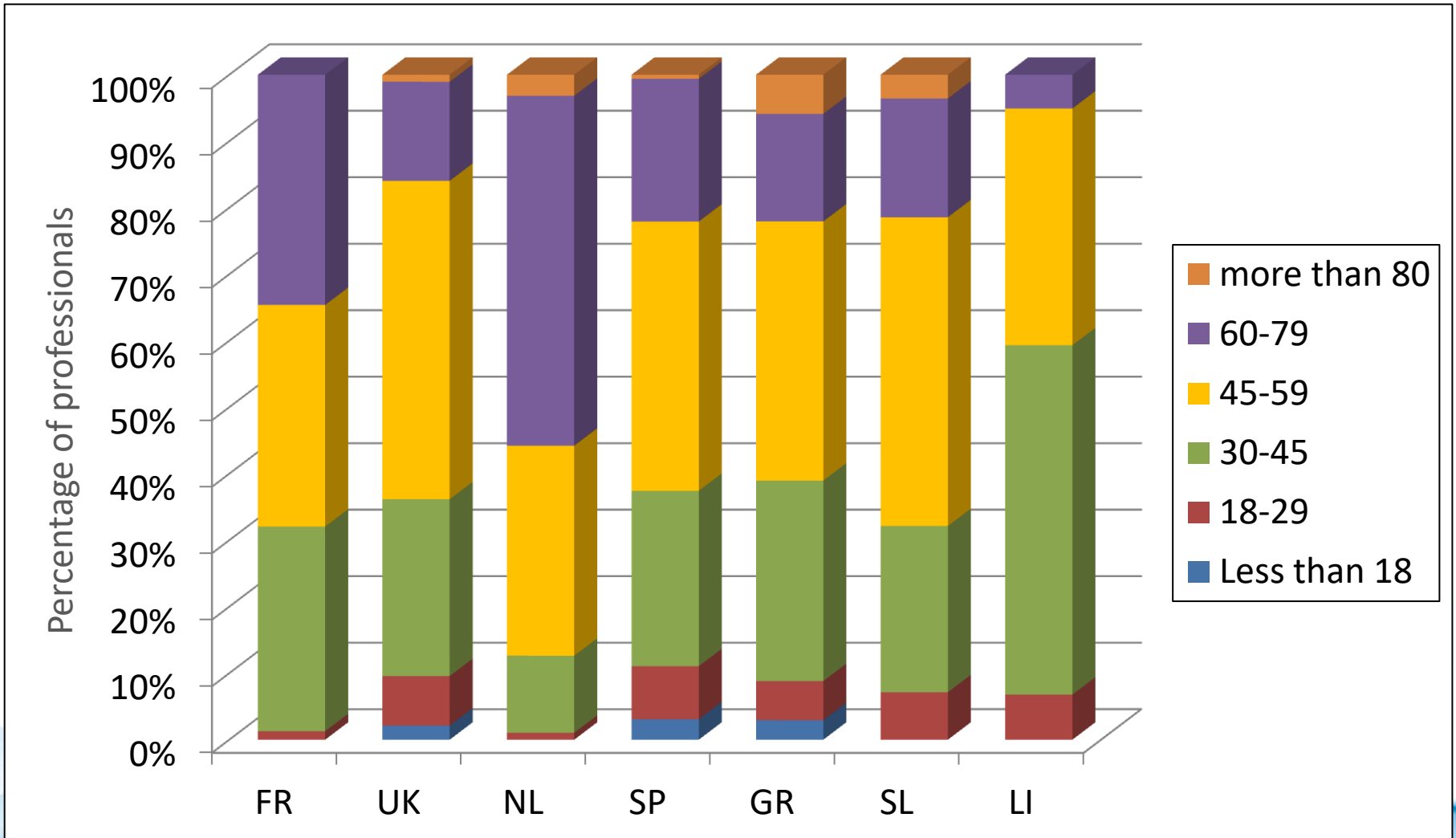
COUNTRY	PATIENTS	PROFESSION.	INHABITANTS	% TP	% PD
Spain	163	120	46	52	13
France	78	55	64	44	7
UK	110	75	65	53	14
Greece	136	101	11	20	6
Lithuania	52	5	3	32	3
Slovenia	28	16	2	33	4
Netherlands	95	49	17	59	15
Portugal	0	9			

Patient views

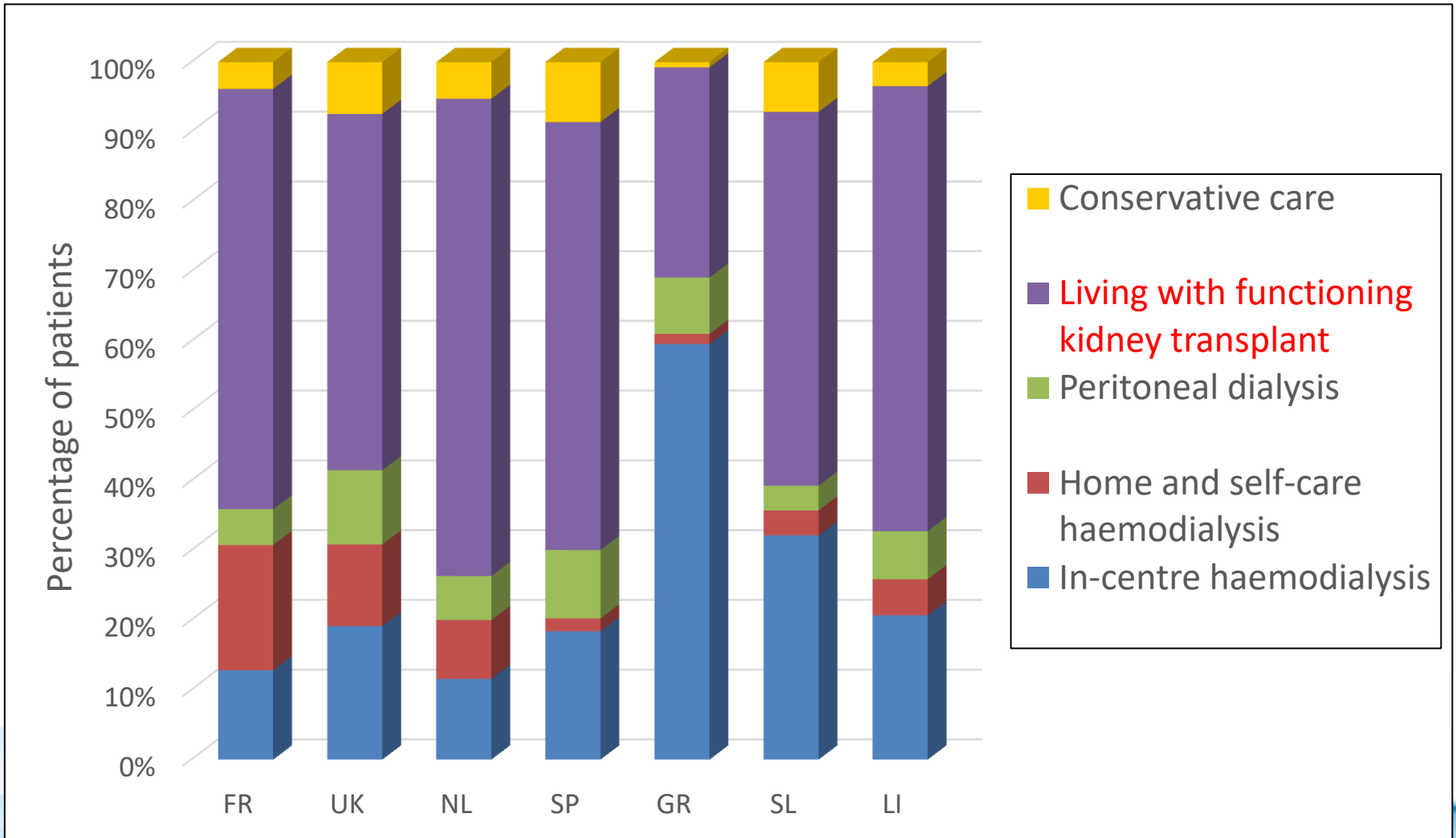
Number of answers per gender



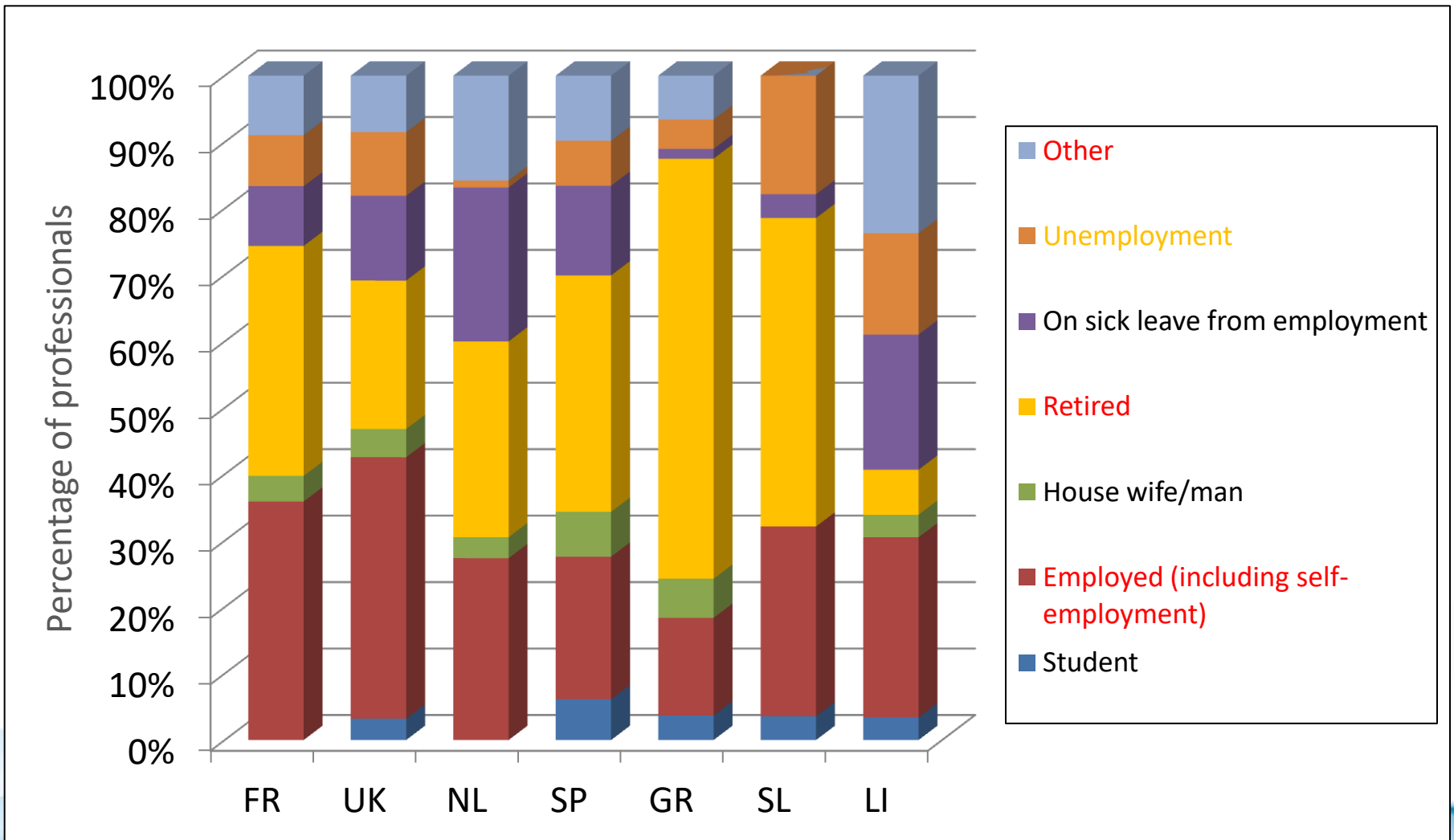
Number of answers per age



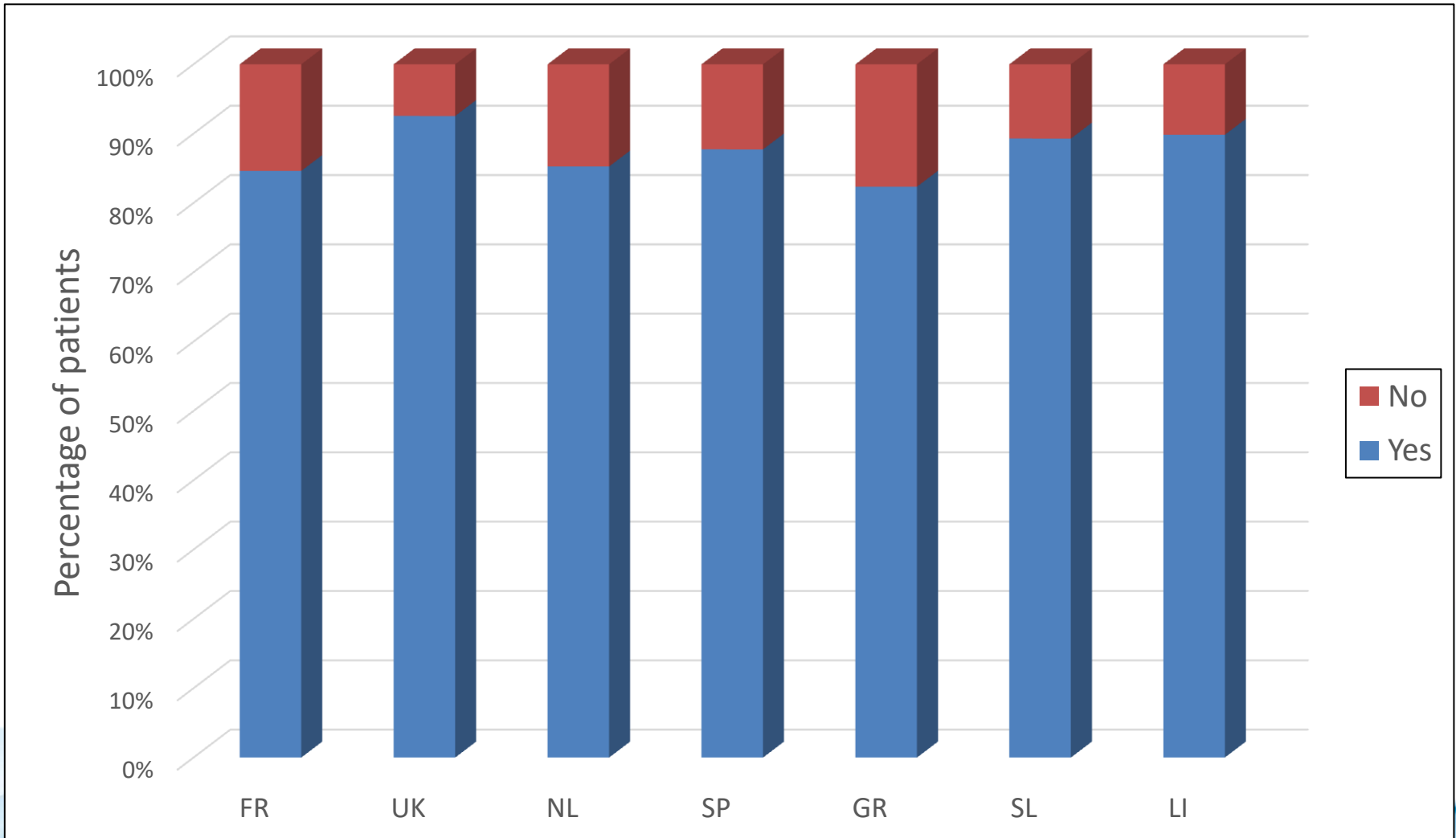
What RRT method are you currently on?



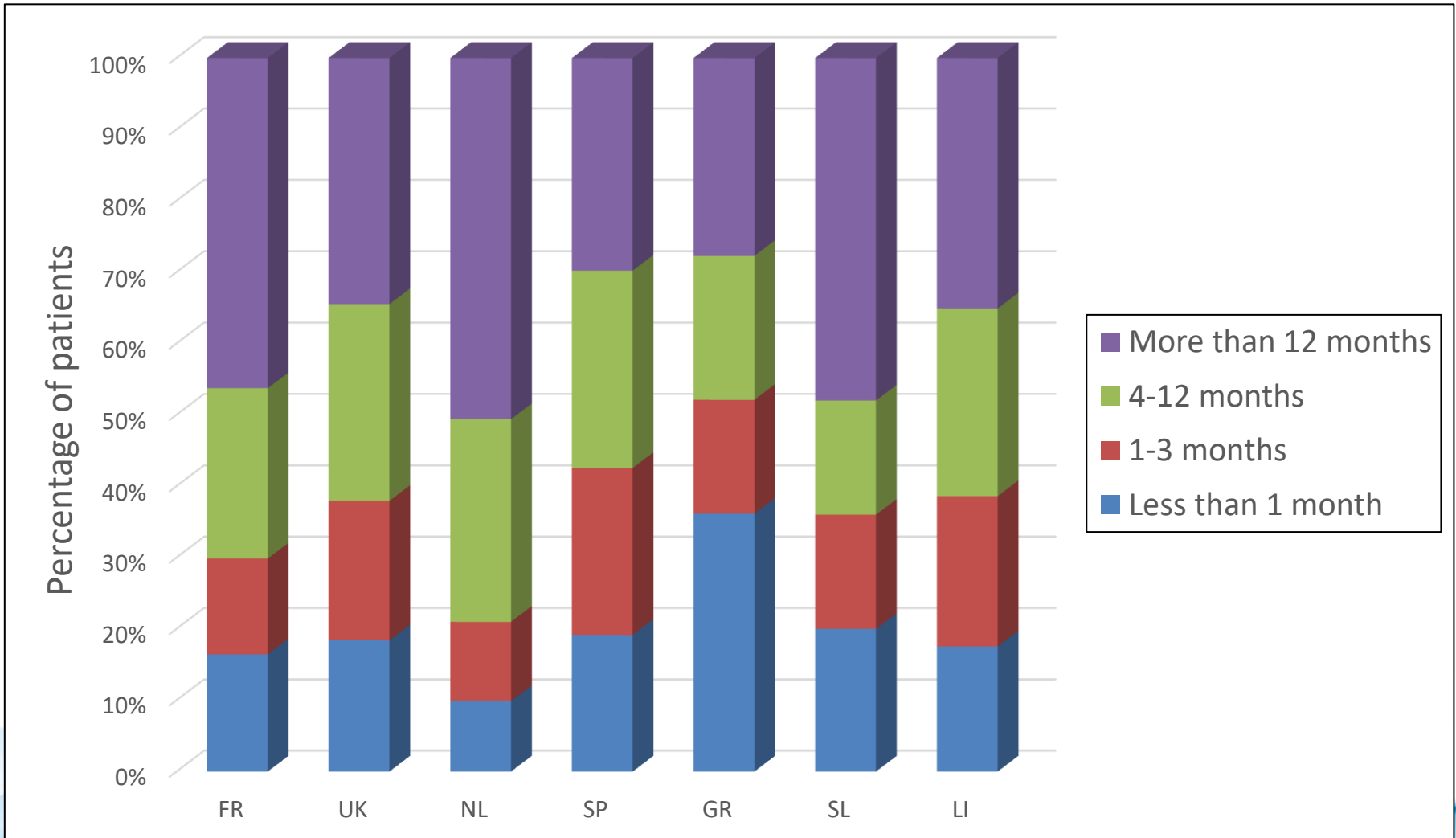
What is your current work status?



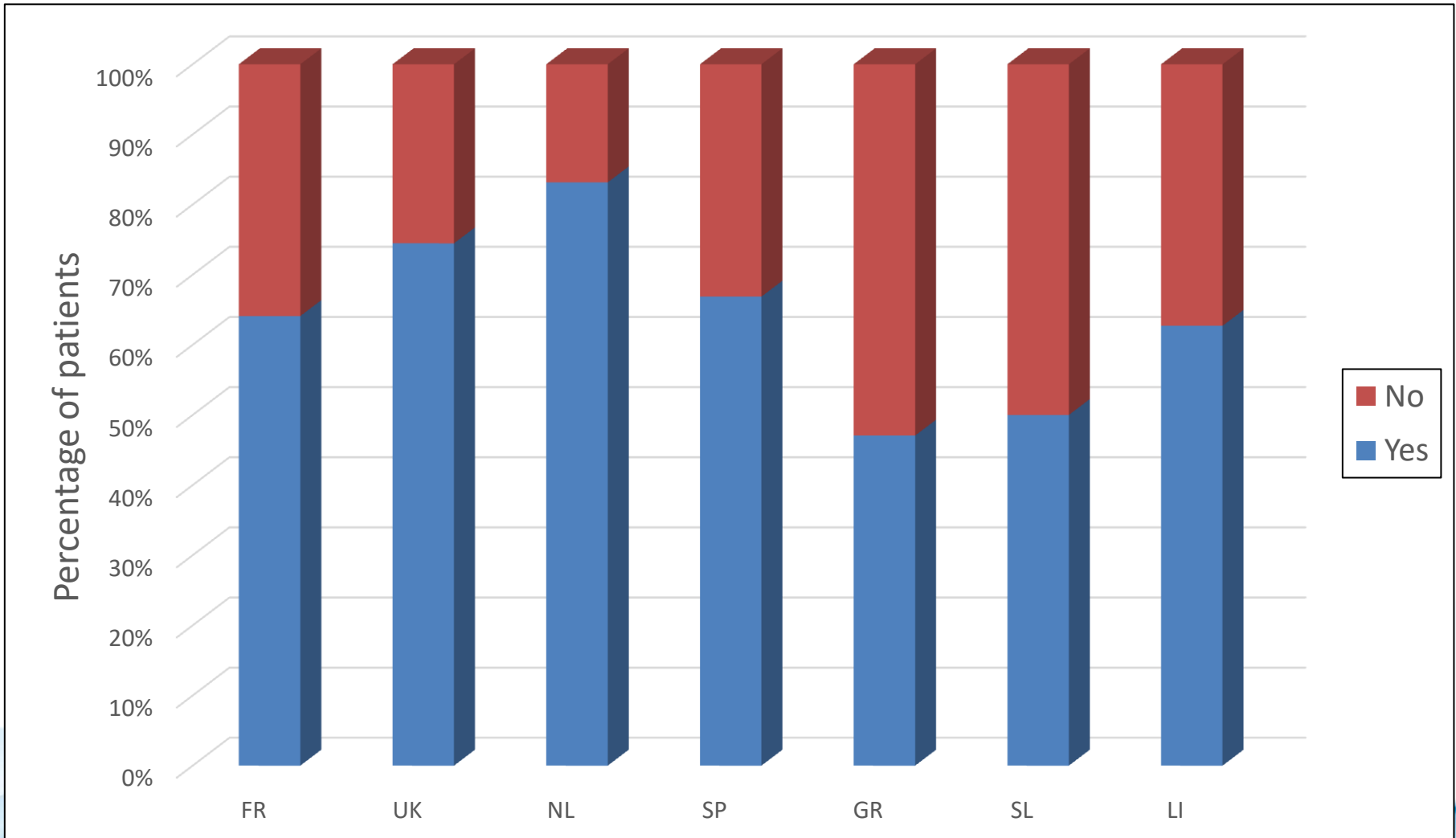
In the period before your start on RRT, were you told that there are different treatment options?



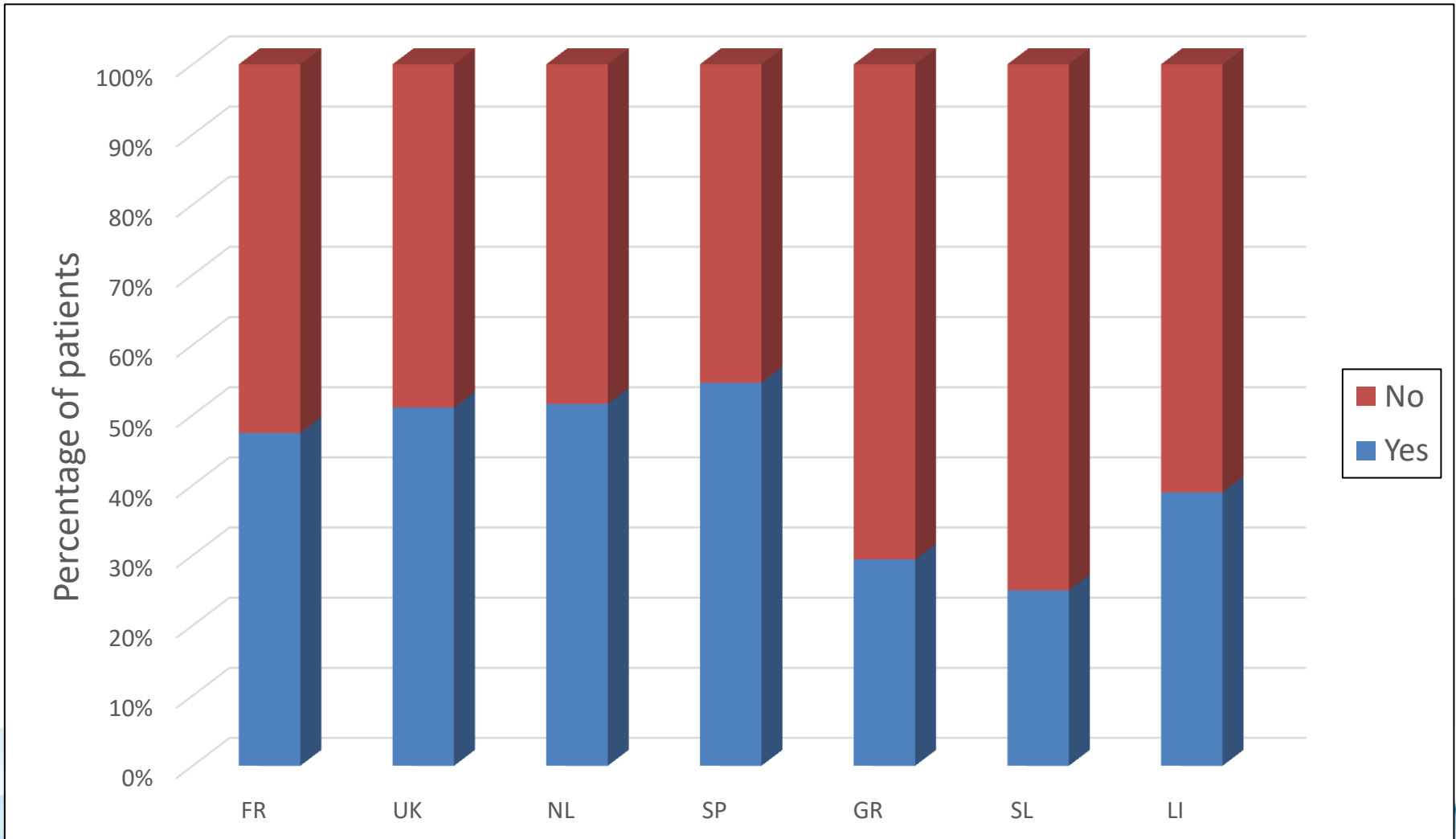
How long before starting were you told that there are different treatment options?



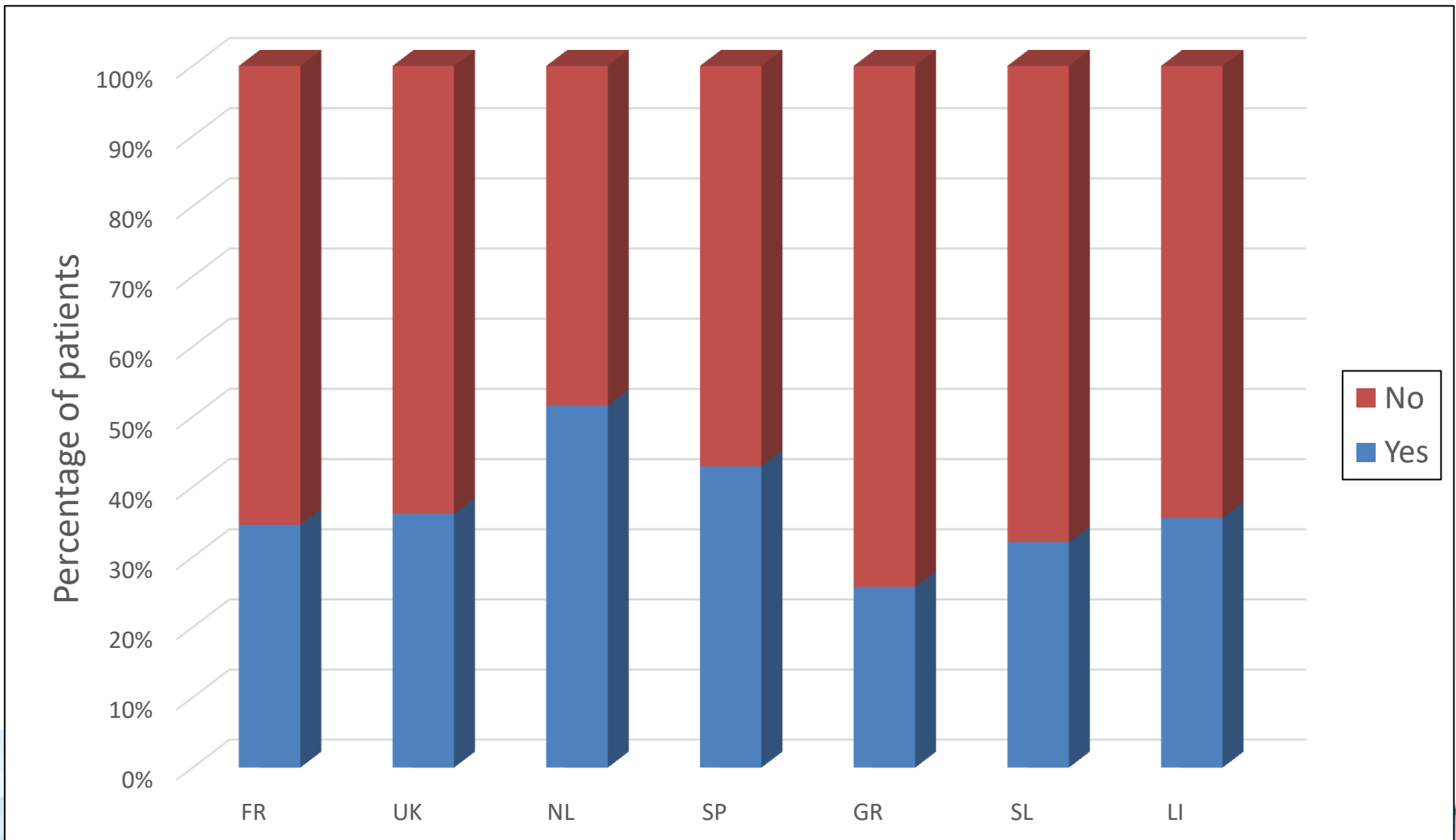
In the period before the start of RRT, do you think you received enough information about peritoneal dialysis?



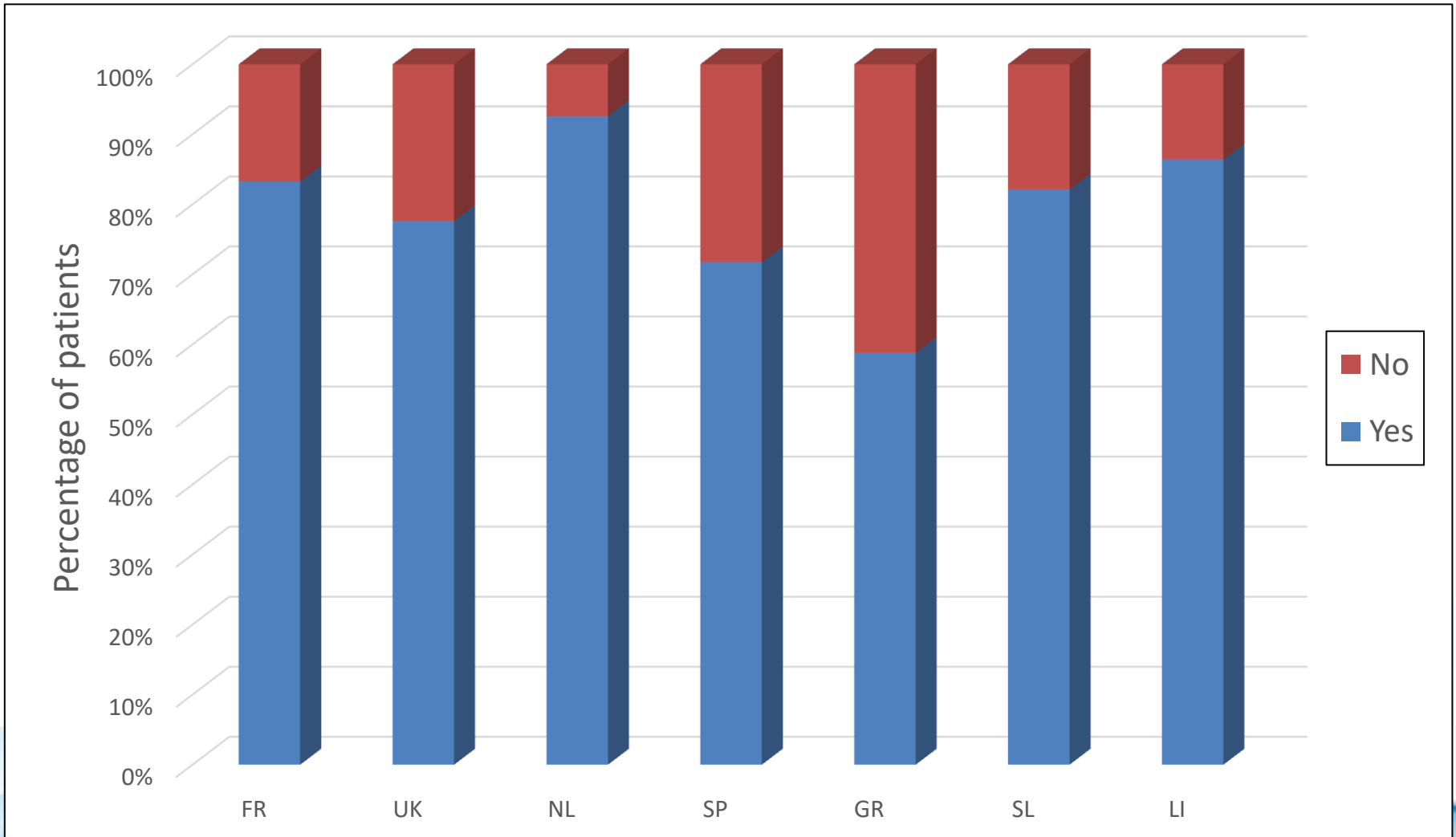
In the period before the start of RRT, do you think you received enough information about home haemodialysis?



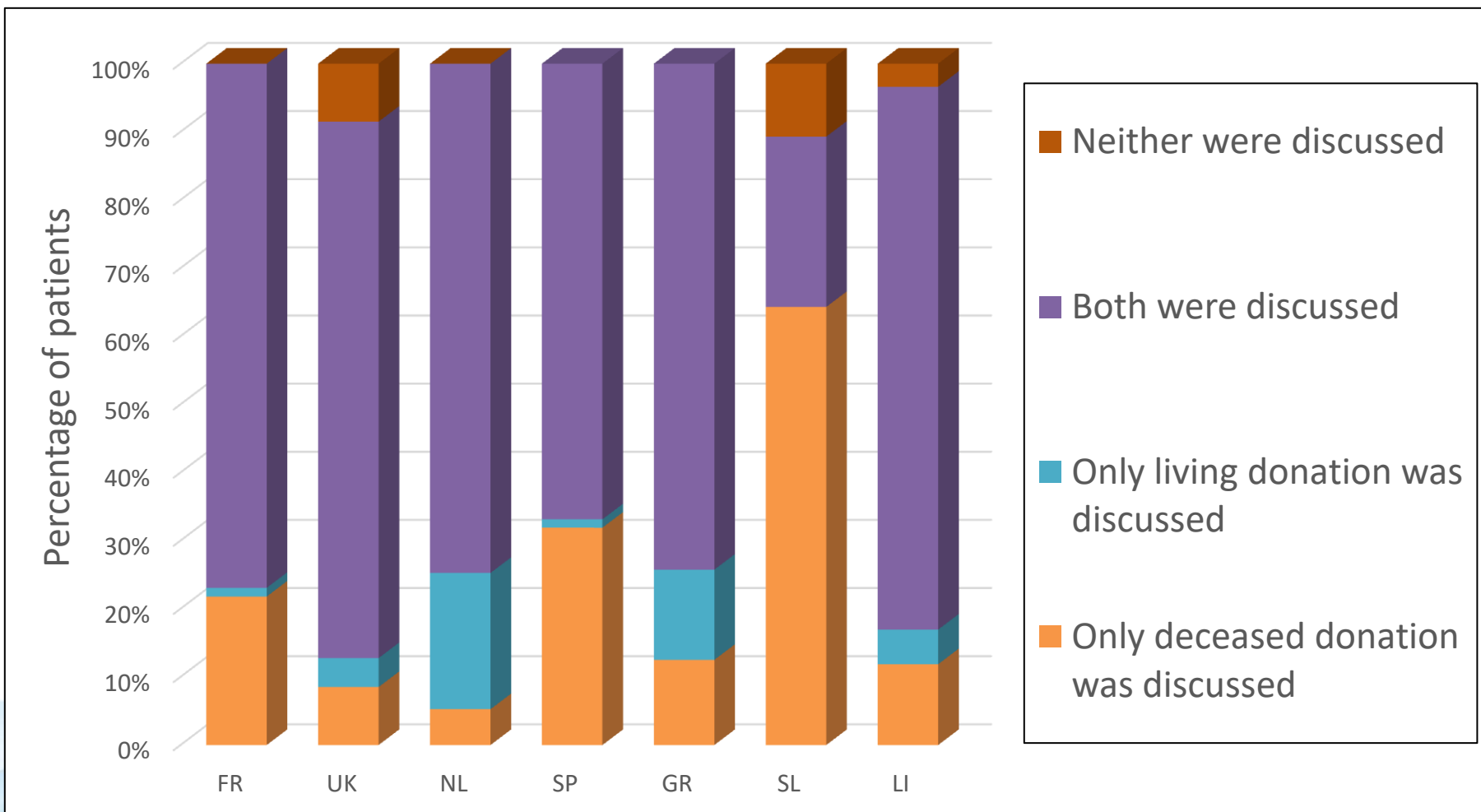
In the period before the start of RRT, do you think you received enough information about overnight haemodialysis?



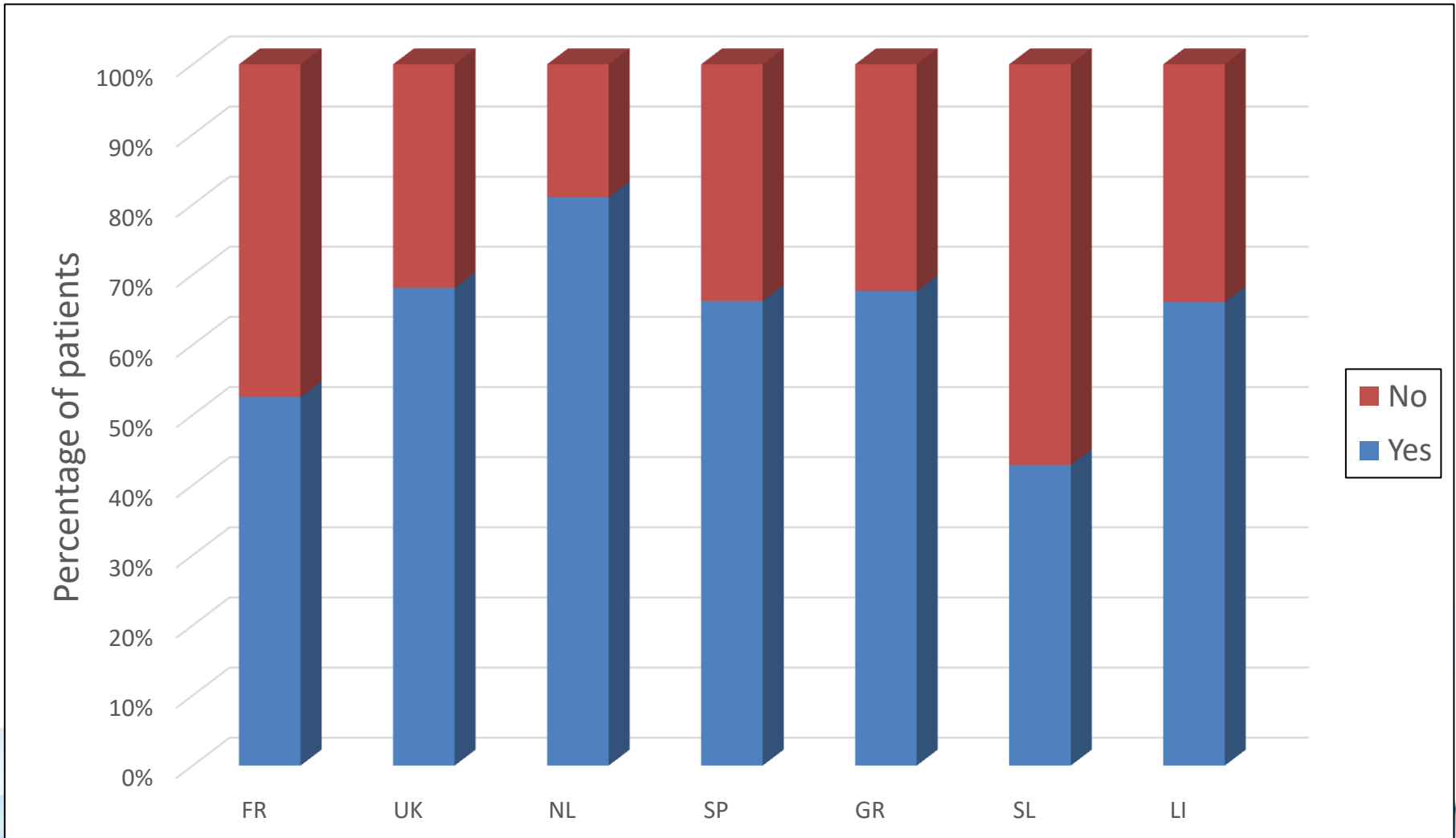
Do you think you received enough information about kidney transplantation (living and deceased donor)?



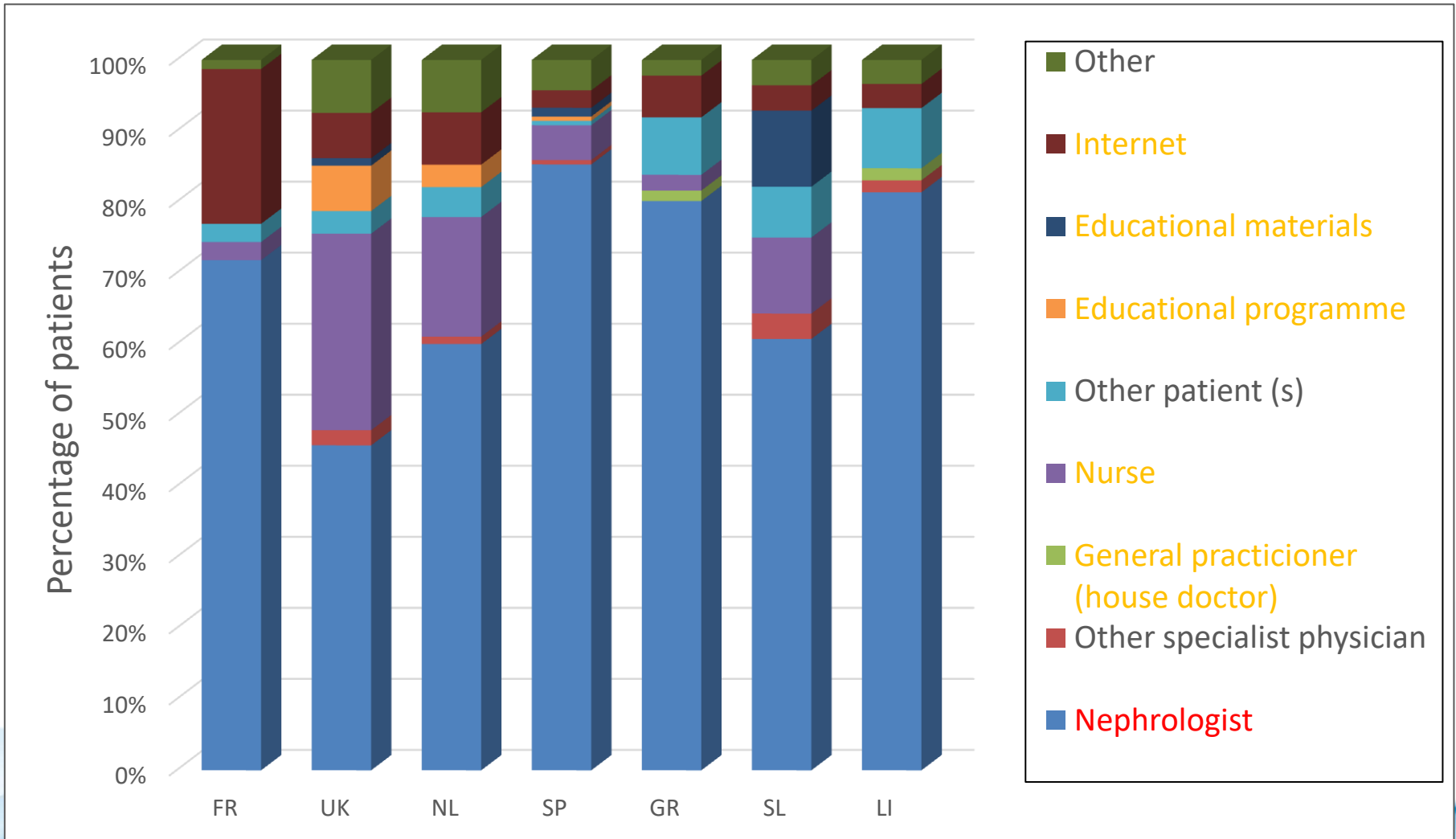
If kidney transplantation was discussed, were all options presented to you?



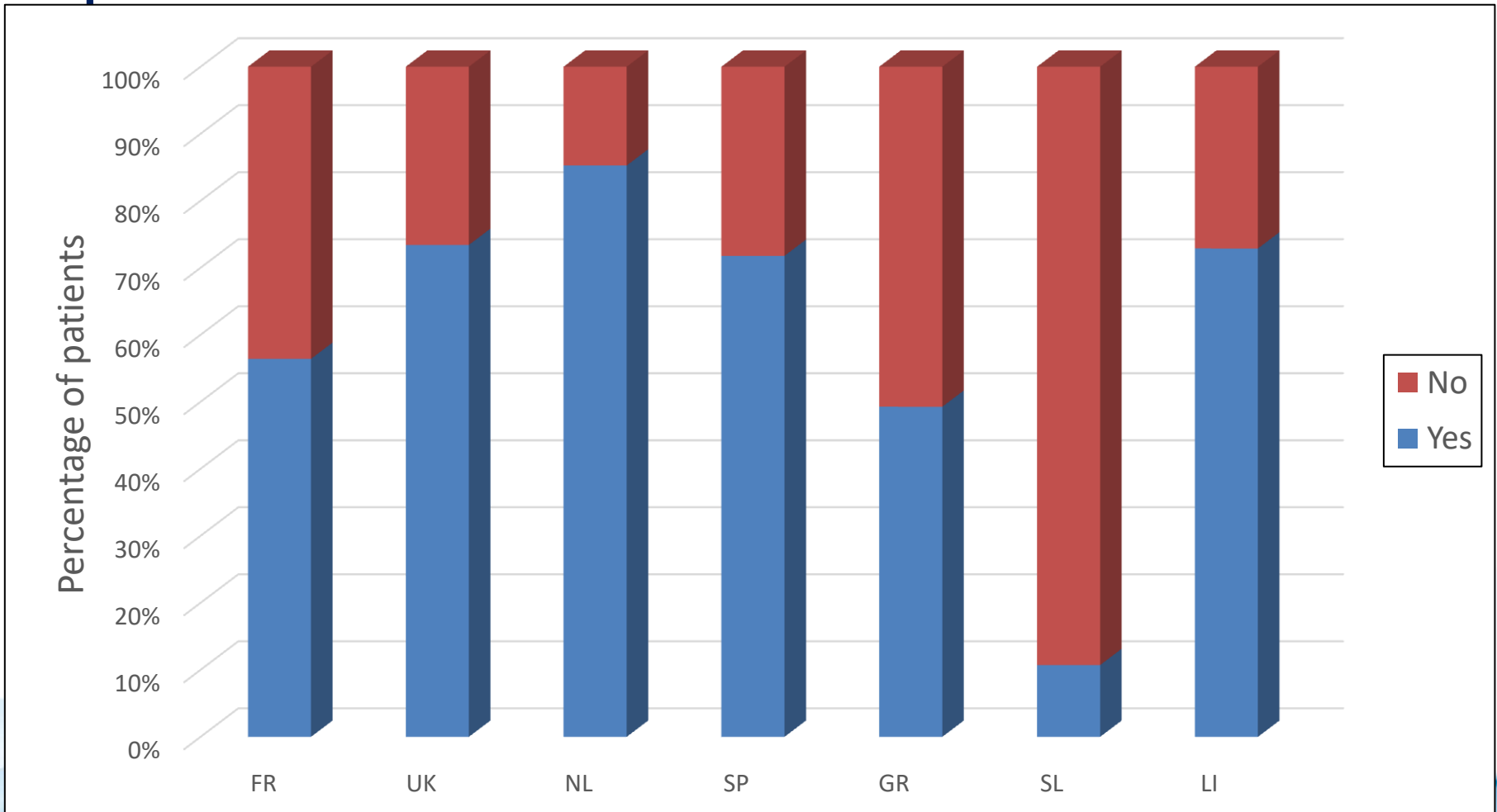
Was your family (spouse, partner, children, parents, other important persons) included in the discussion?



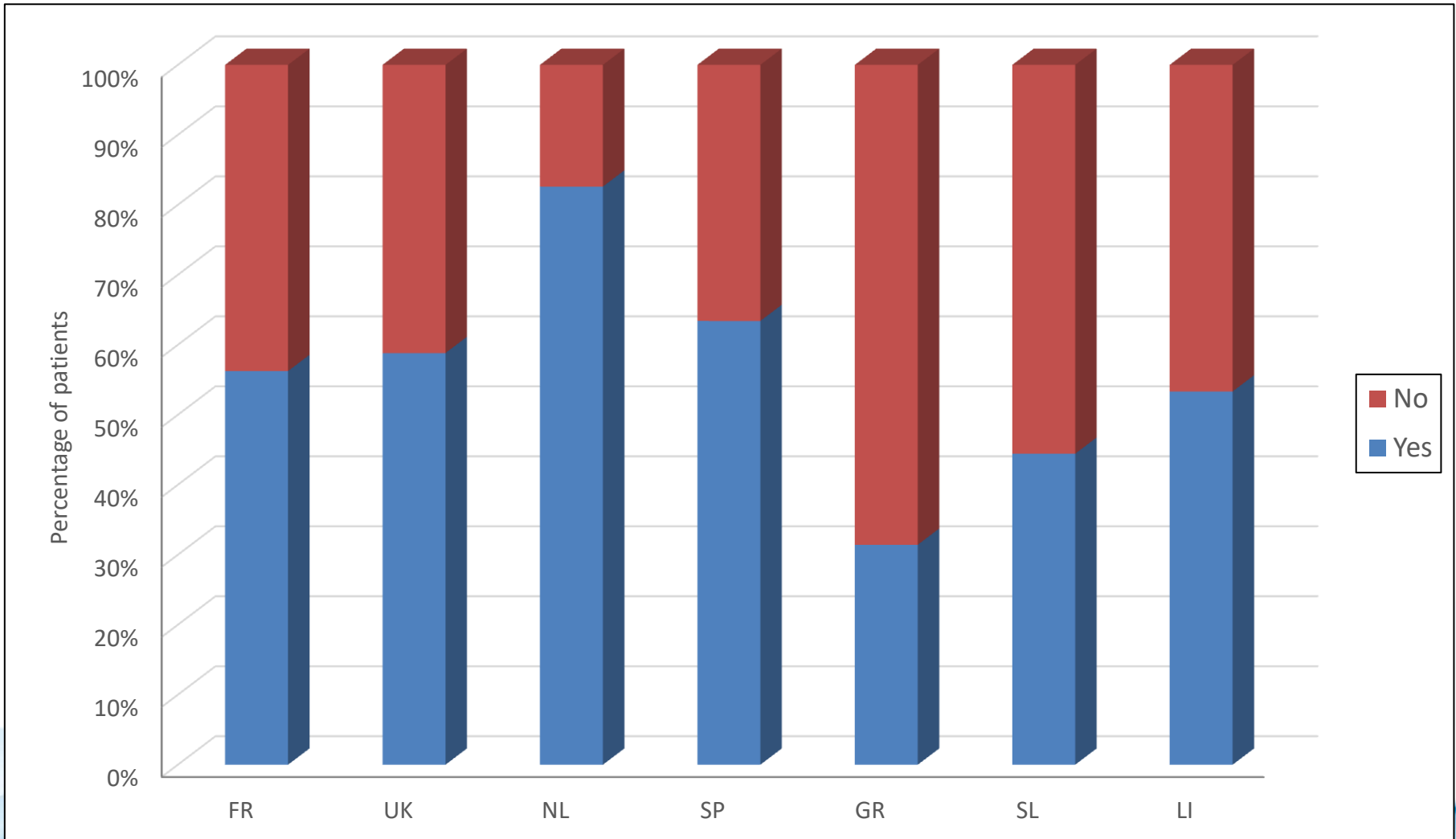
Which person or source offered you the most useful information about RRT?



If different treatment methods were discussed with you, were you given a choice of which one you preferred to proceed with?

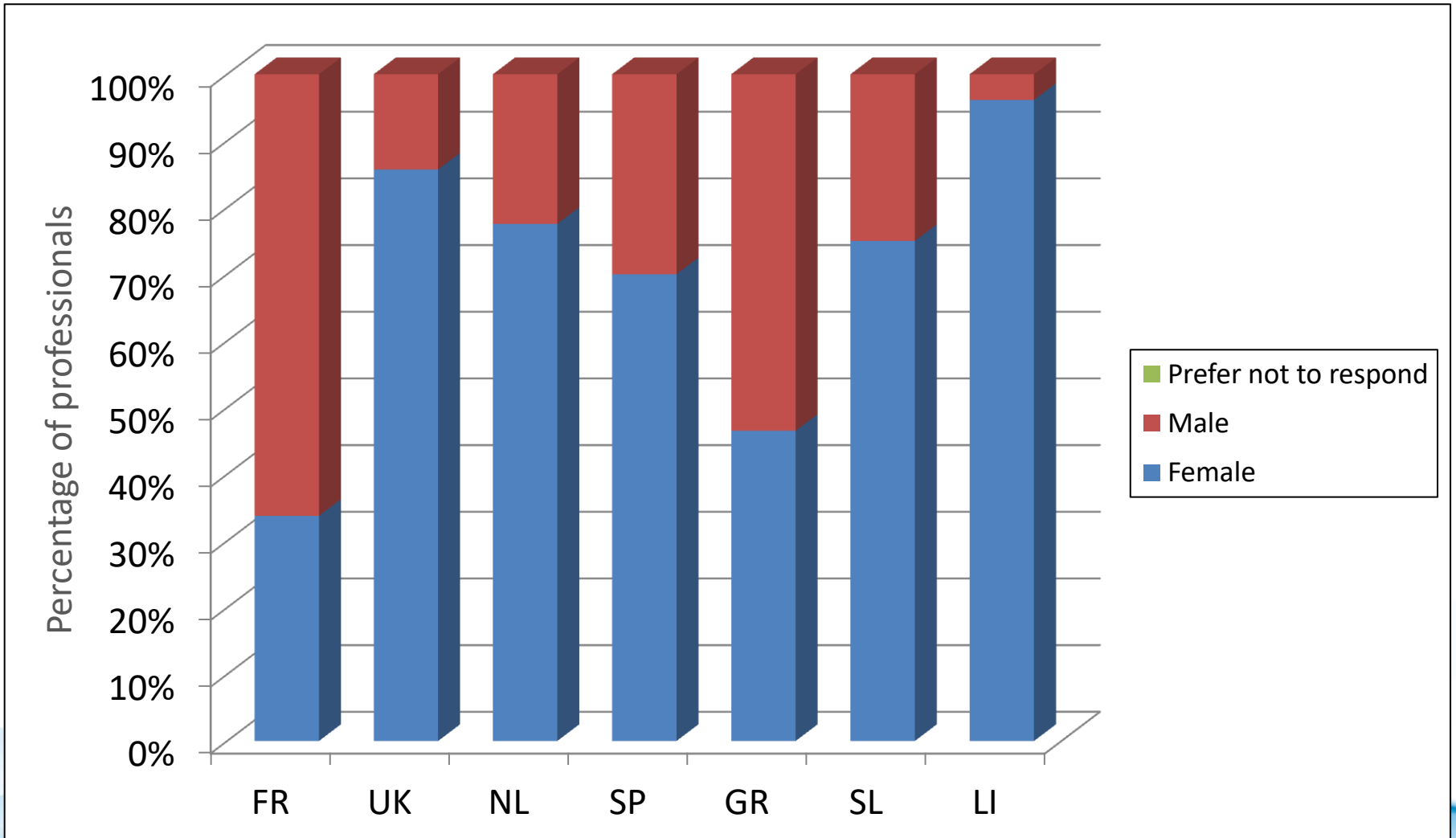


If you wanted to change treatment, was your wish then addressed by your health care professional

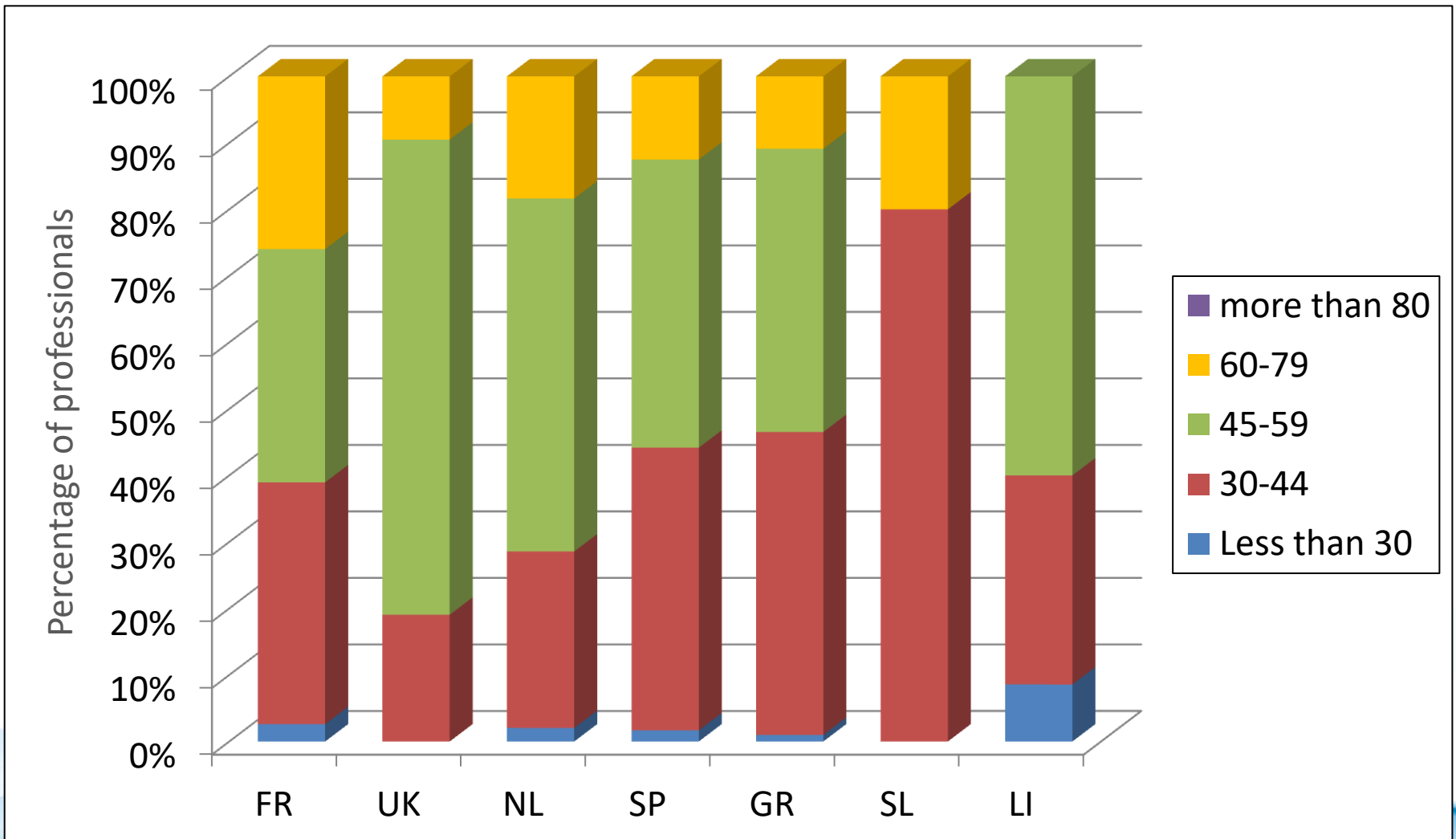


Physician & nurse views

Number of answers per gender



Number of answers per age



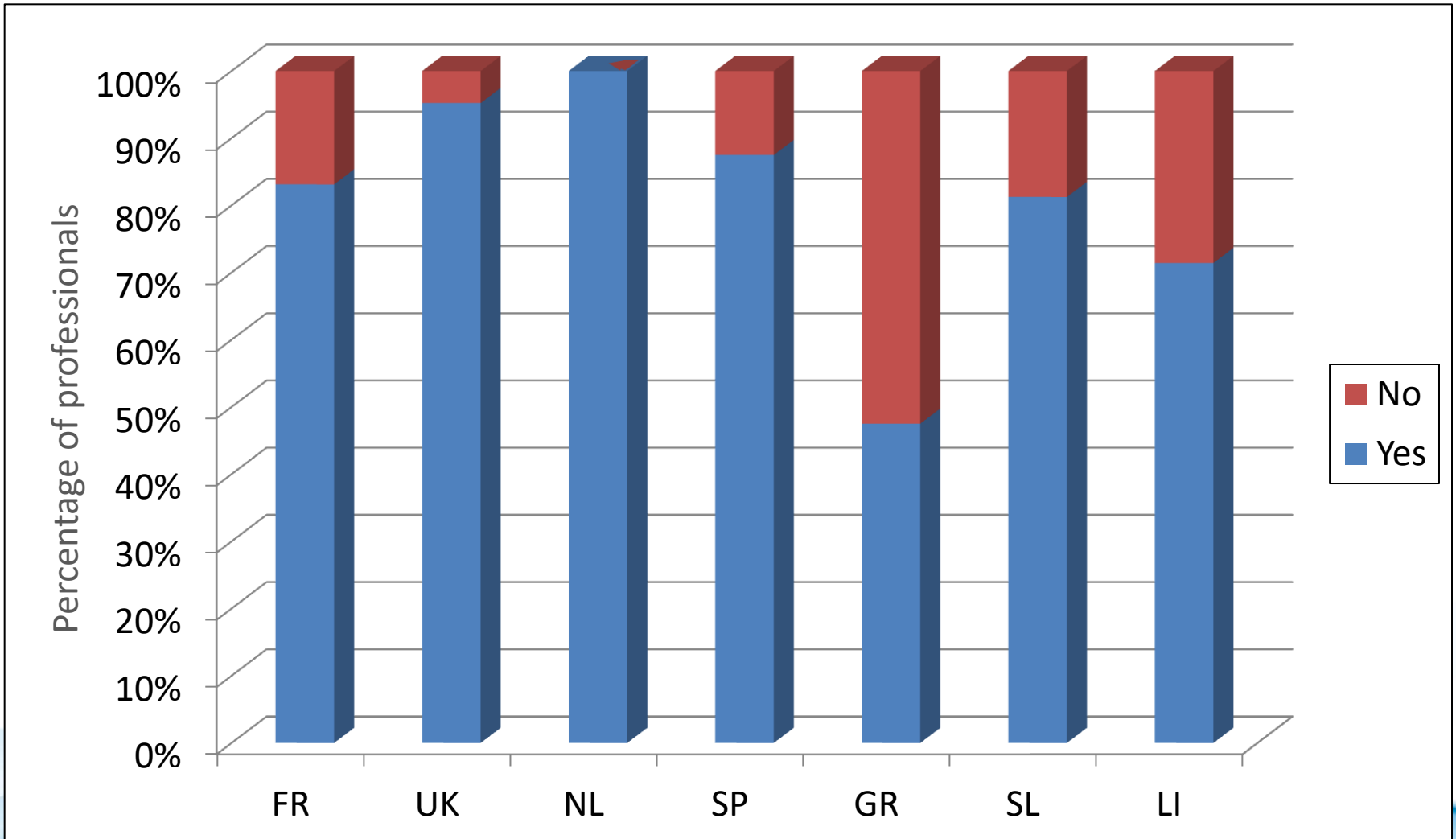
Distribution of respondents

	TOTAL	MD (%)	NURSE (%)
France	74	100	0
UK	17	53	47
The Netherlands	38	11	89
Spain	117	30	70
Greece	97	88	12
Slovenia	12	75	35
Lithuania	33	94	6

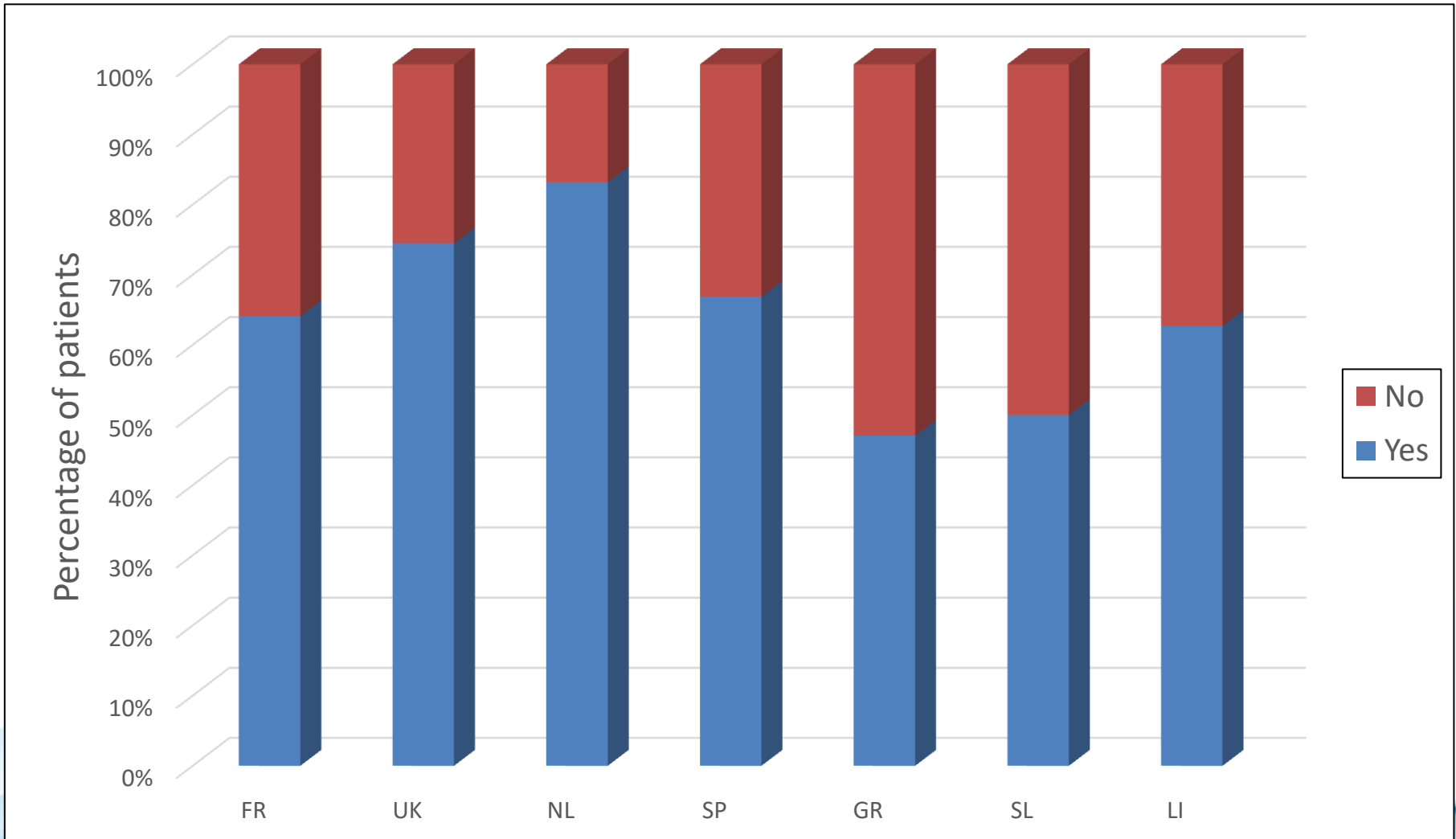
Distribution of respondents

	TOTAL	MD (%)	NURSE (%)
France	74	100	0
UK	17	53	47
The Netherlands	38	11	89
Spain	117	30	70
Greece	97	88	12
Slovenia	12	75	35
Lithuania	33	94	6
		64	36

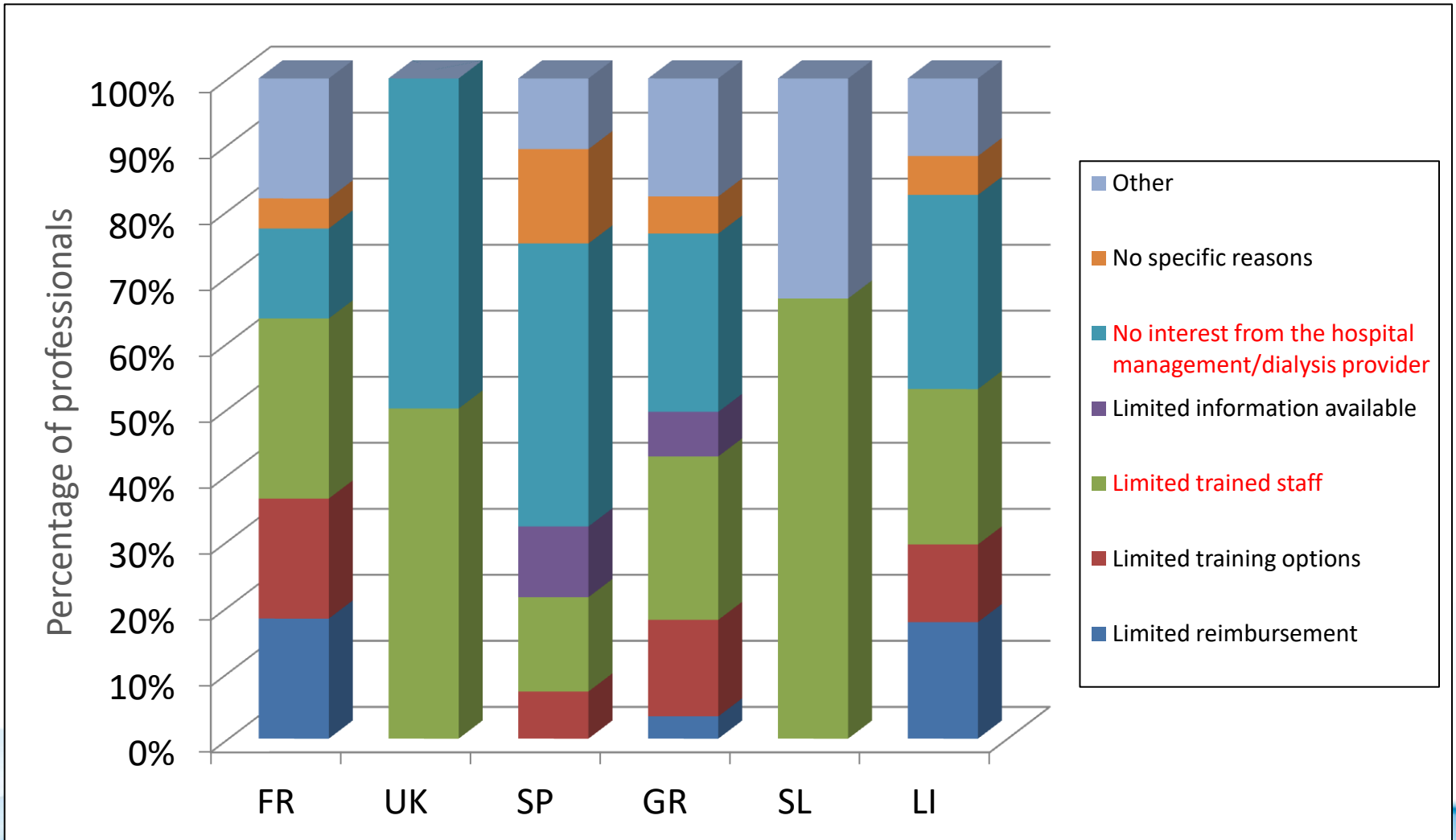
In your centre, is it a standard procedure to offer candidates for RRT information about peritoneal dialysis?



Patient view: In the period before the start of RRT, do you think you received enough information about peritoneal dialysis?



In your centre, is it a standard procedure to offer candidates for RRT information about peritoneal dialysis? - if no, why?



Thanks & Acknowledgments

Special thanks to the following EKHA members and organisations for helping us to carryout this survey:



LINKS TO PARTICIPATE

- **POLAND**

- Patients: <https://www.surveymonkey.com/r/9VGRSSN>
- Professionals:
<https://www.surveymonkey.com/r/7BCNK2N>

- **PORTUGAL**

- Patients: <https://www.surveymonkey.com/r/KL6XSLB>
- Professionals:
<https://www.surveymonkey.com/r/BM6PG6V>

- **Contacts:**

- raymond.vanholder@ugent.be
- sara.martin@ekha.eu

CONCLUSIONS (1)



- Substantial heterogeneity among countries

CONCLUSIONS (1)



- Substantial heterogeneity among countries
- In no country all options are offered at 100%

CONCLUSIONS (1)



- Substantial heterogeneity among countries
- In no country all options are offered at 100%
- Lack of patient education for sustainable options

CONCLUSIONS (1)



- Substantial heterogeneity among countries
- In no country all options are offered at 100%
- Lack of patient education for sustainable options
- Some sustainable options are not offered due to

CONCLUSIONS (1)



- Substantial heterogeneity among countries
- In no country all options are offered at 100%
- Lack of patient education for sustainable options
- Some sustainable options are not offered due to
 - Lack of interest by the hospital/dialysis provider

CONCLUSIONS (1)



- Substantial heterogeneity among countries
- In no country all options are offered at 100%
- Lack of patient education for sustainable options
- Some sustainable options are not offered due to
 - Lack of interest by the hospital/dialysis provider
 - Lack of specifically trained staff

CONCLUSIONS (2)



- Among TP options, living donation is often discriminated

CONCLUSIONS (2)



- Among TP options, living donation is often discriminated
- Not offering an option is often part of a vicious circle (no patient information, no demand, no offering, no patient information)

CONCLUSIONS (2)



- Among TP options, living donation is often discriminated
- Not offering an option is often part of a vicious circle (no patient information, no demand, no offering, no patient information)
- Free choice is hampered by financial drivers and lack of trained staff

CONCLUSIONS (2)



- Among TP options, living donation is often discriminated
- Not offering an option is often part of a vicious circle (no patient information, no demand, no offering, no patient information)
- Free choice is hampered by financial drivers and lack of trained staff
- The opinion of the patient and his/her family are often neglected

LINKS TO PARTICIPATE

- **POLAND**

- Patients: <https://www.surveymonkey.com/r/9VGRSSN>
- Professionals:
<https://www.surveymonkey.com/r/7BCNK2N>

- **PORTUGAL**

- Patients: <https://www.surveymonkey.com/r/KL6XSLB>
- Professionals:
<https://www.surveymonkey.com/r/BM6PG6V>

- **Contacts:**

- raymond.vanholder@ugent.be
- sara.martin@ekha.eu

Back-ups

Recommendations to improve Patient's Access to Choice of Treatment



Back-ups

Treatment reimbursement strategies

EKHA maintains that all therapies should be accessible to all patients throughout Europe. In order to safe-guard this right, **a better distribution of healthcare spending and cost savings is required.**

Key asks:

- 1. Patient-centred decision-making** in renal replacement therapy
- 2. Fair access and distribution** of care modalities across regions
- 3. Social impact** should be considered in the search for technological innovation
- 4. Option for conservative care if appropriate**

Recommendations to improve Patient's Access to Choice of Treatment



Home care is not widely available yet it has many **benefits**, including:

- **Flexibility**
- **Lower Cost**

Key asks:

1. **Share and implement best practices** which encourage home care for kidney patients
2. **Educate health care professionals to advise on Conservative Care** including information on patient-centred, palliative care

Recommendations to improve Patient's Access to Choice of Treatment

Increase access to Transplantation

Transplantation is the treatment of choice for end-stage kidney disease

- **Better quality of life**
- **Lower cost**

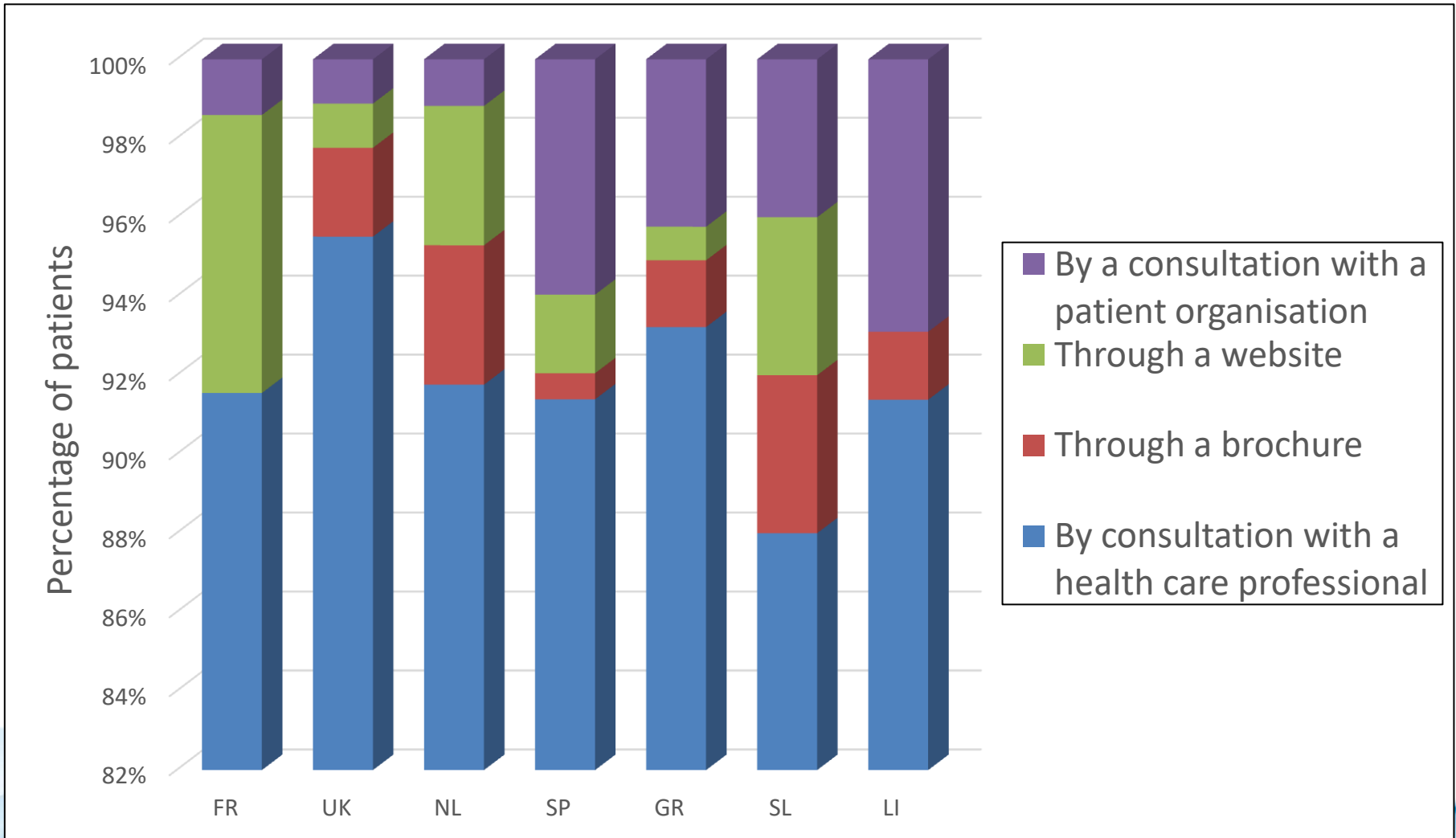
Key asks:

- 1. Fund programmes that help increase organ donation (living and deceased)**
- 2. Encourage opting-out donor policies in Member States**

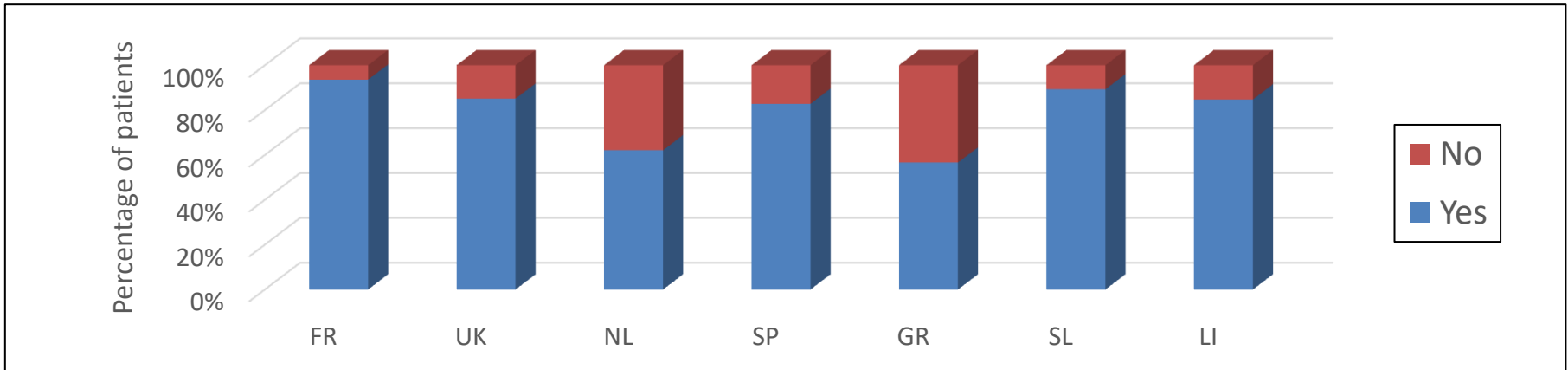
umesc
Kasih
Mamnoon
Todah
Diolch
Kiitos
Sheun
Shnorhakalutun
Gamsahapnida
Te^oekkir
Dekuju/Dekujeme
Hvala
Shokriya
Ngiyabonga
Dziekuję
Shokrun
Spaas
Mul
Ači
Dank
Daw
Waad
Dhanyavaadaalu
Takk
Kop
Salamat
Merci
Gra
or
al
Xie
Dankie
Dhanyavaad
Grazie
Faleminderit
Krap
Dhanyavadaalu
Dhanyavad
Khopjai
Kruthagnathalu
Arigatou
Faleiminderit
Tack
Grazi
raibh
Gracias
Nandree
Blagodariya
Fyrir
Terima
Enkosi
Danke
dank
Euxaristo
Kun
Shukriya
Shukriya
Kun
Shukriya
or
ederim
Hain
Dhan
daa
Asante

backups

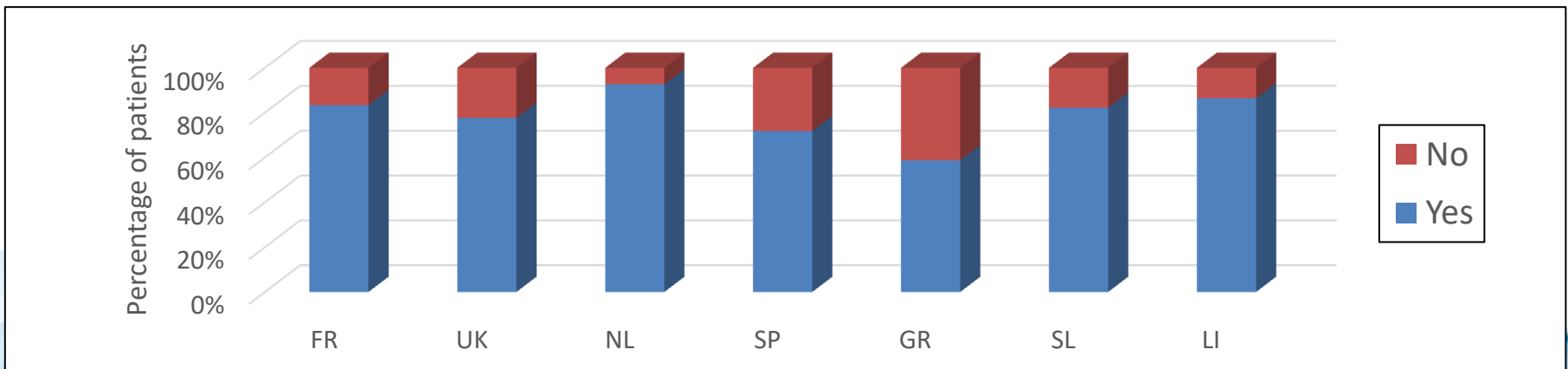
How were you given this information?



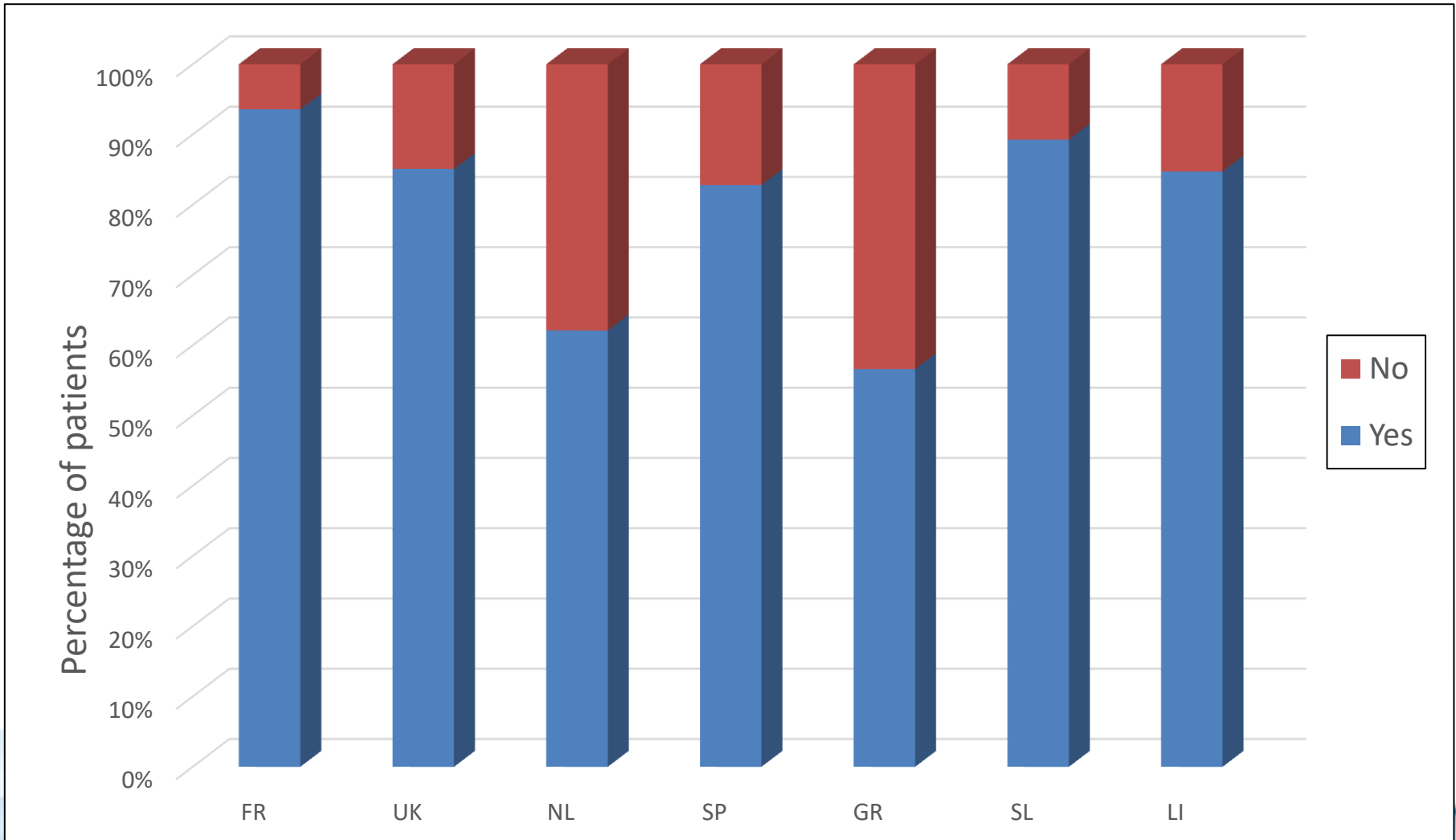
Are you now, or have you ever been on a waiting list for a kidney transplantation?



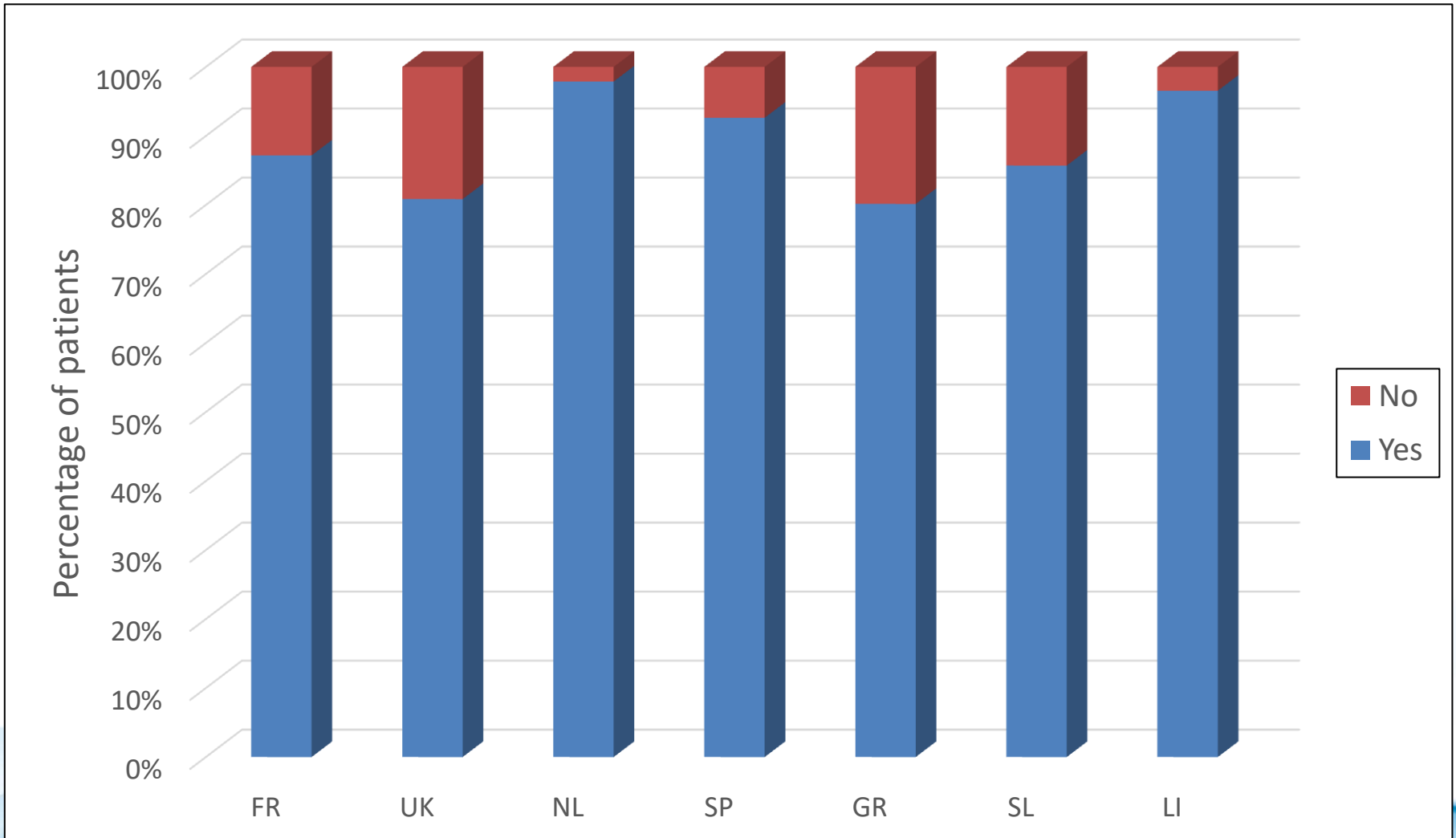
Do you think you received enough information about kidney transplantation (living and deceased donor)?



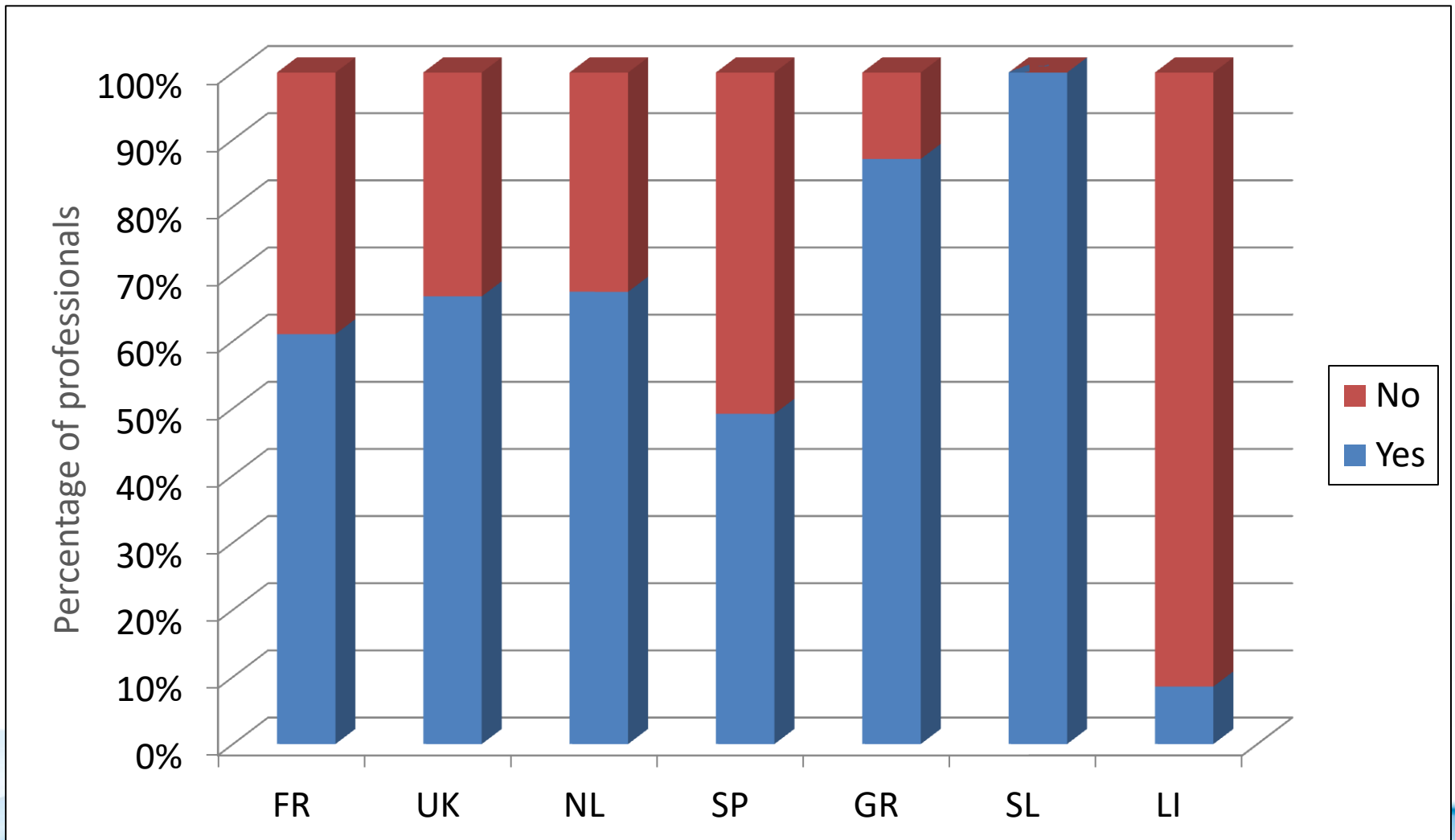
Are you now, or have you ever been on a waiting list for a kidney transplantation?



Is this treatment, in your opinion, the best option for you?



In your centre, is it a standard procedure to offer candidates for RRT information about home haemodialysis?



In your opinion, are patients in your centre actively involved in the choice of their treatment?

If no, what are the circumstances which do not allow for patient choice?

In your opinion, are patients given the option to change their treatment regime if they wish?

If no, can you specify the reason?

If treatment options are limited, which treatment would you like to see given more resources/attention in your health system or centre?



Conclusions

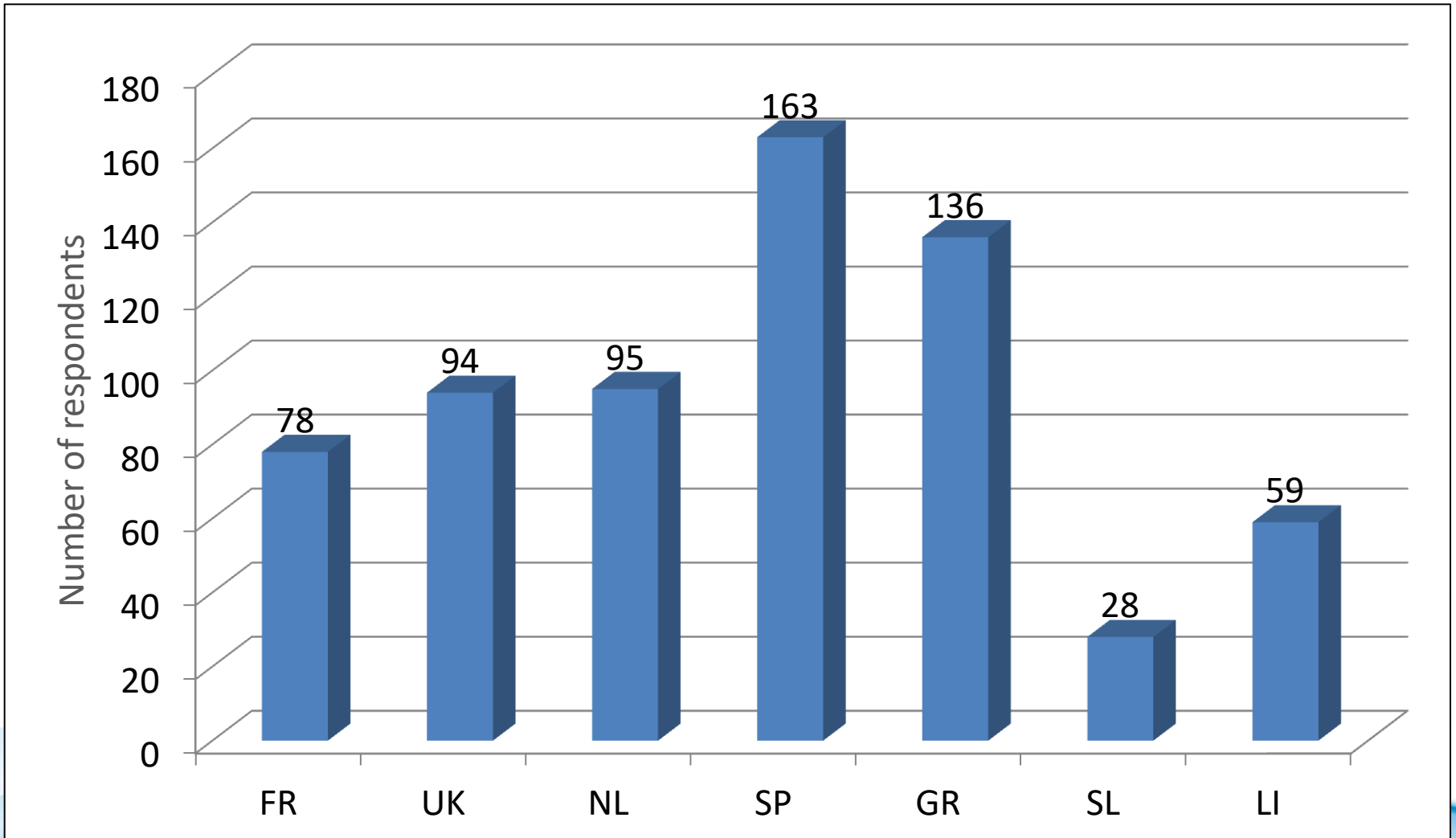
- Text xxxxxxxxxxxxxxxx
- Text xxxxxxxxxxxxxxxx
- Text xxxxxxxxxxxxxxxx

Recommendations

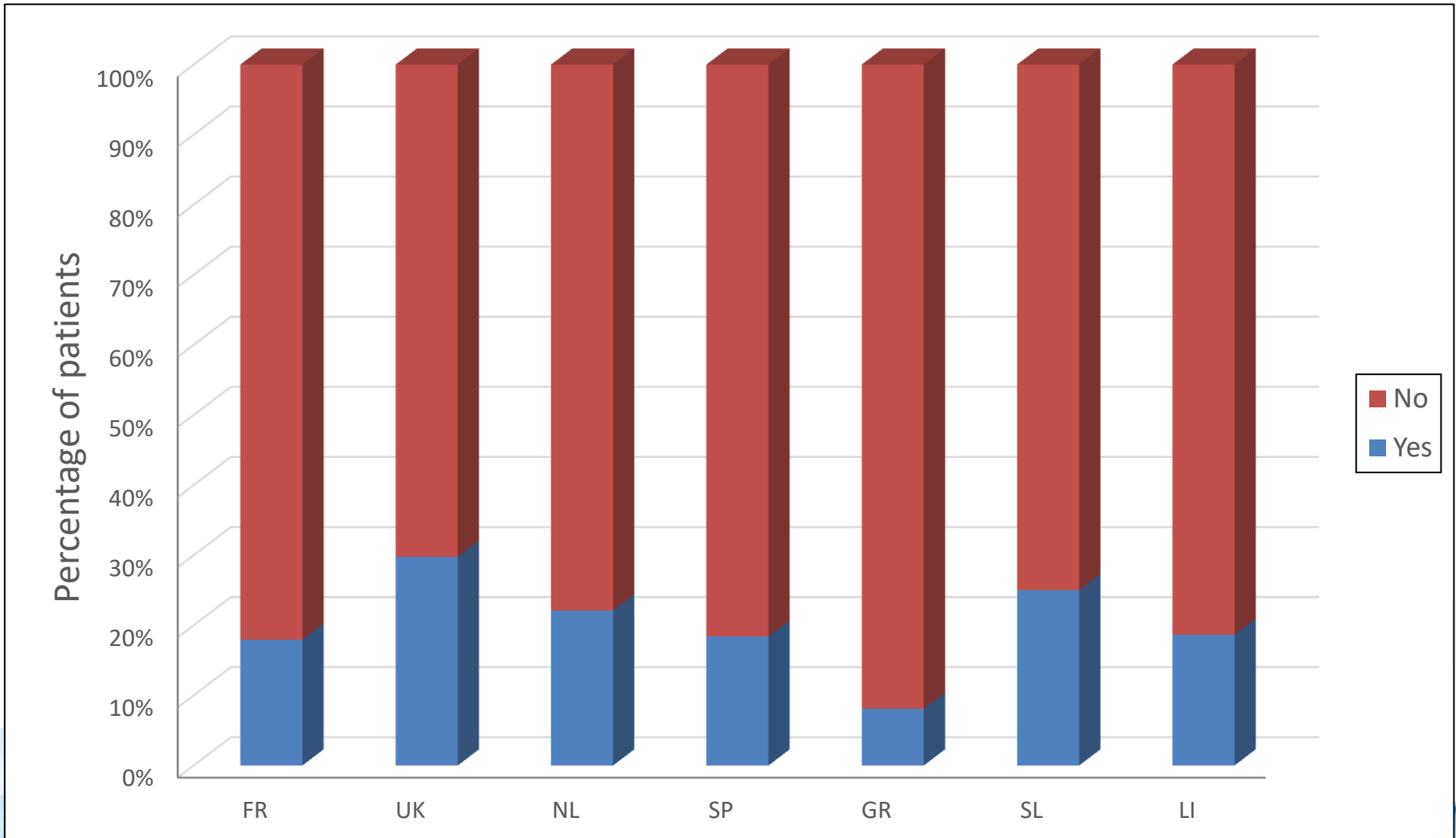
- Text xxxxxxxxxxxxxxxx
- Text xxxxxxxxxxxxxxxx
- Text xxxxxxxxxxxxxxxx



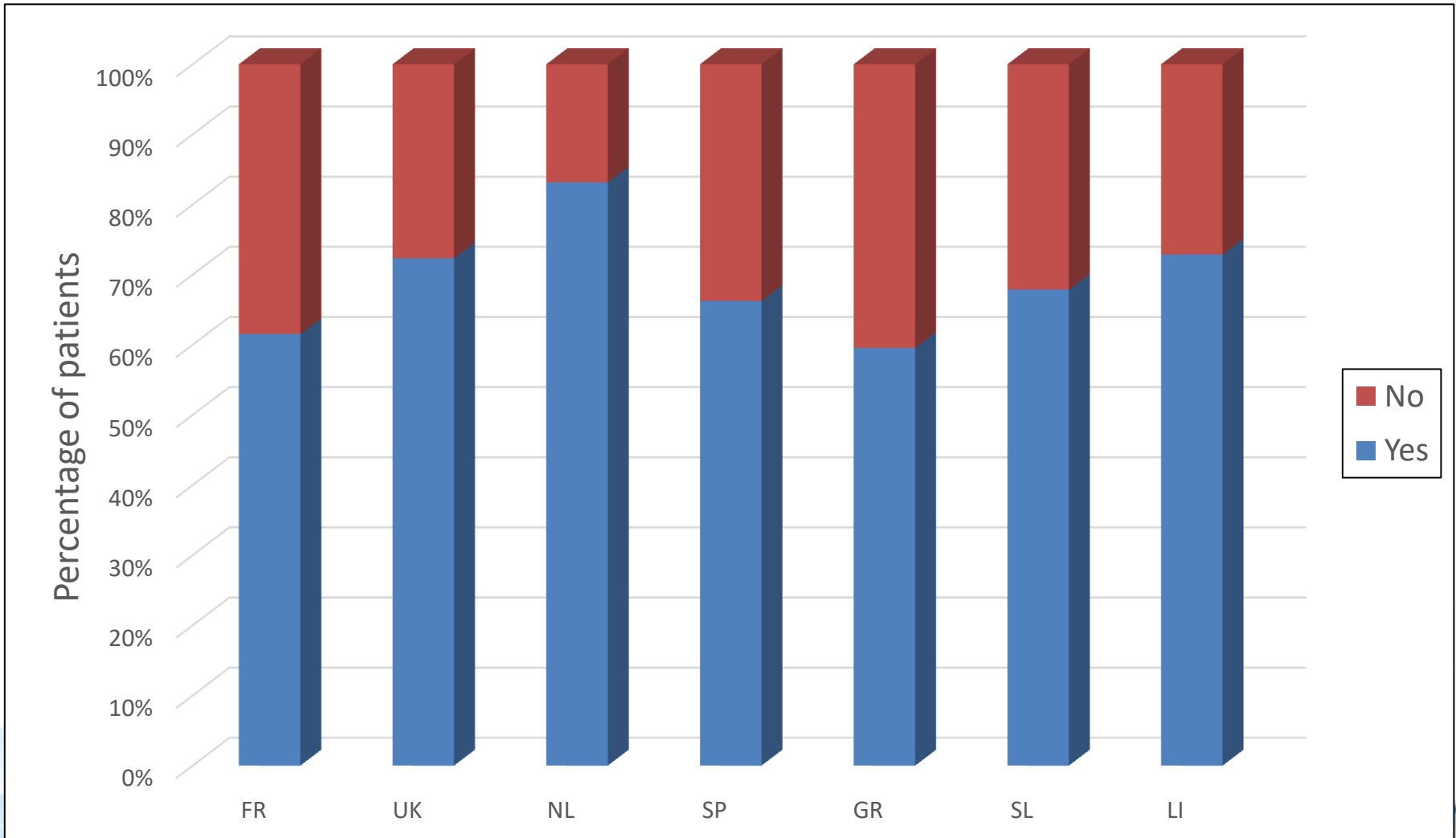
Number of answers per country



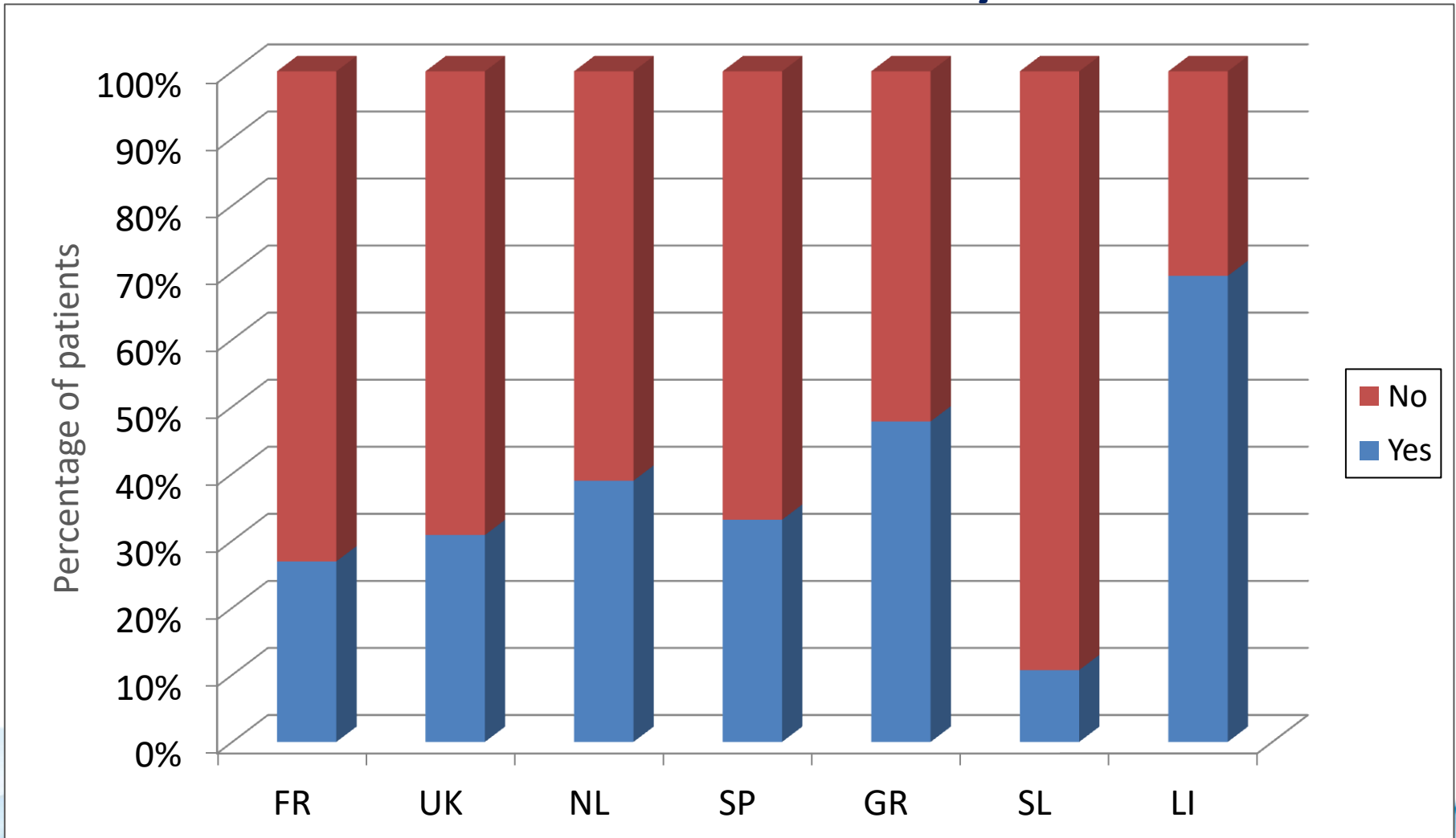
During your time on RRT, have you wanted to change to a different treatment method?



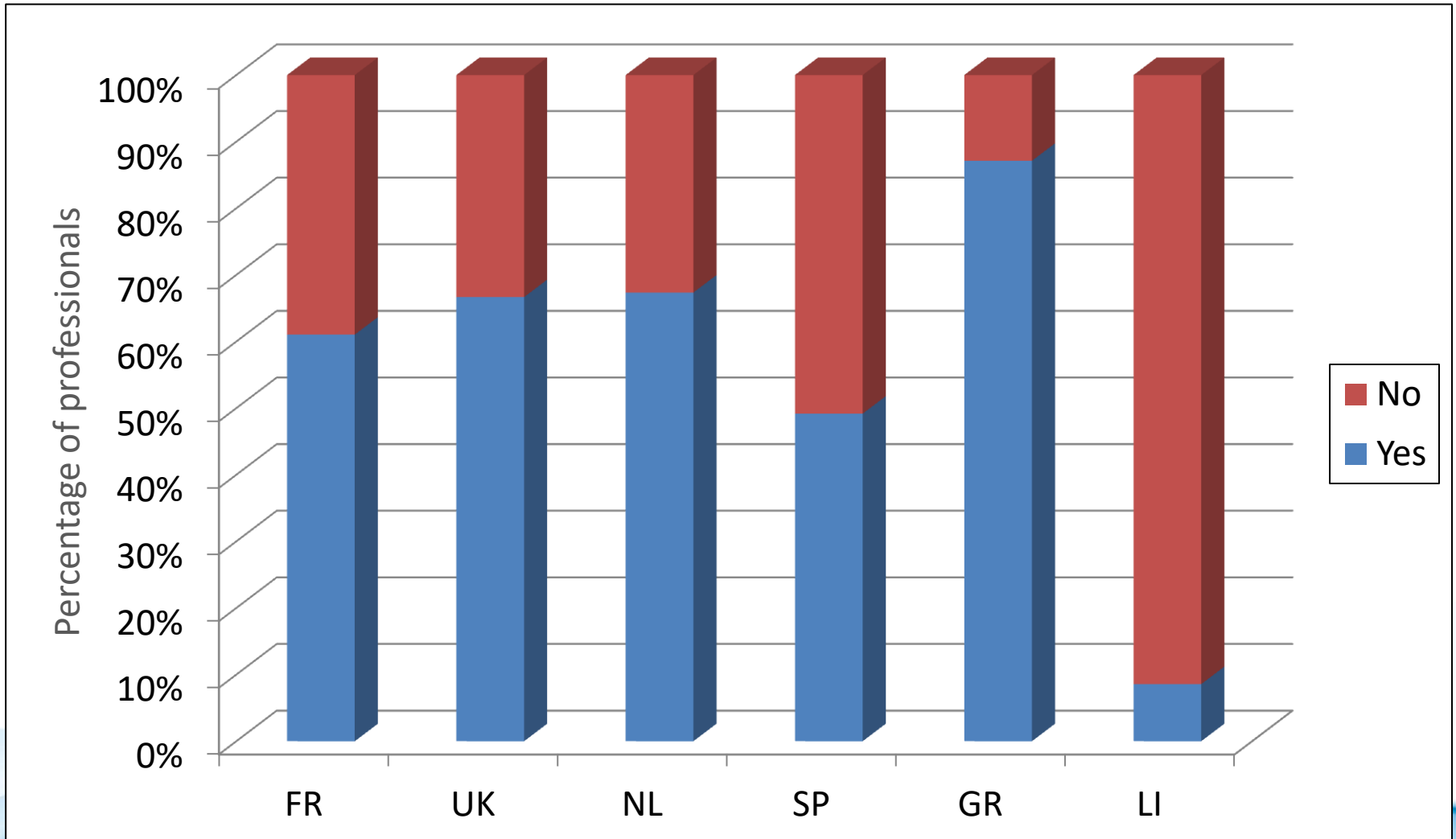
In the period before the start of RRT, do you think you received enough information about in-centre haemodialysis?



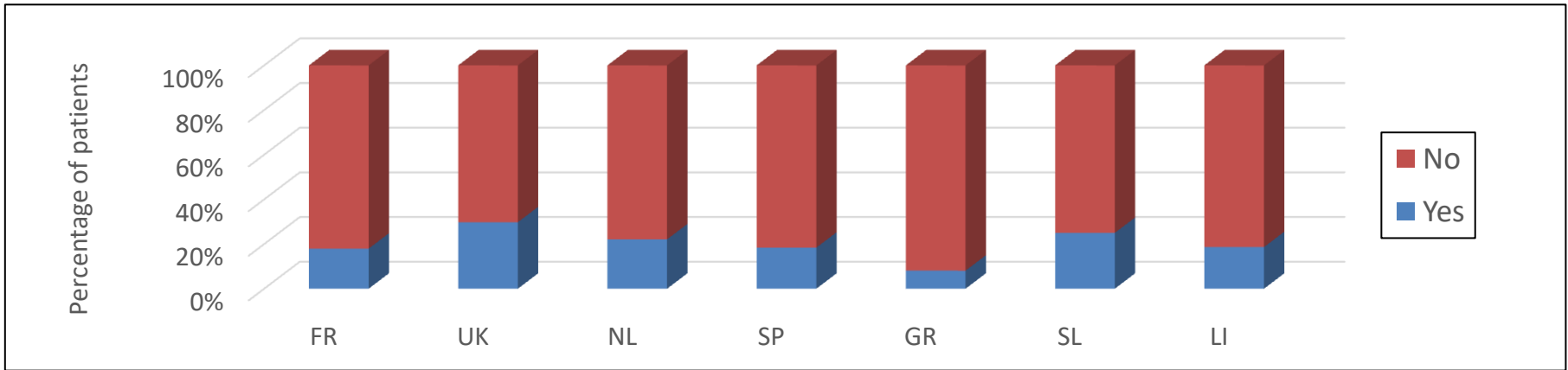
In the period before the start of RRT, was the option of conservative care discussed with you?



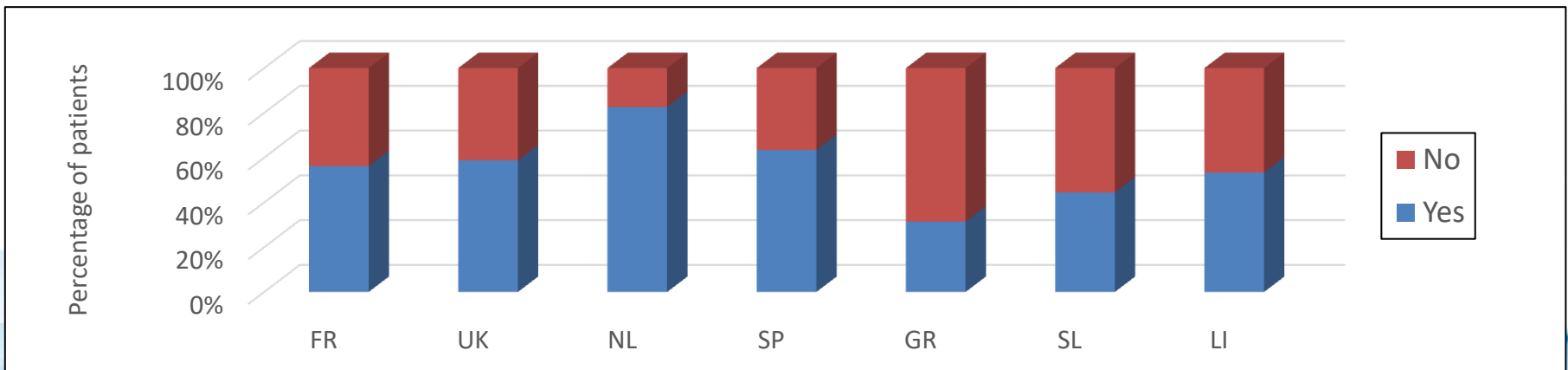
In your centre, is it a standard procedure to offer candidates for RRT information about home haemodialysis?



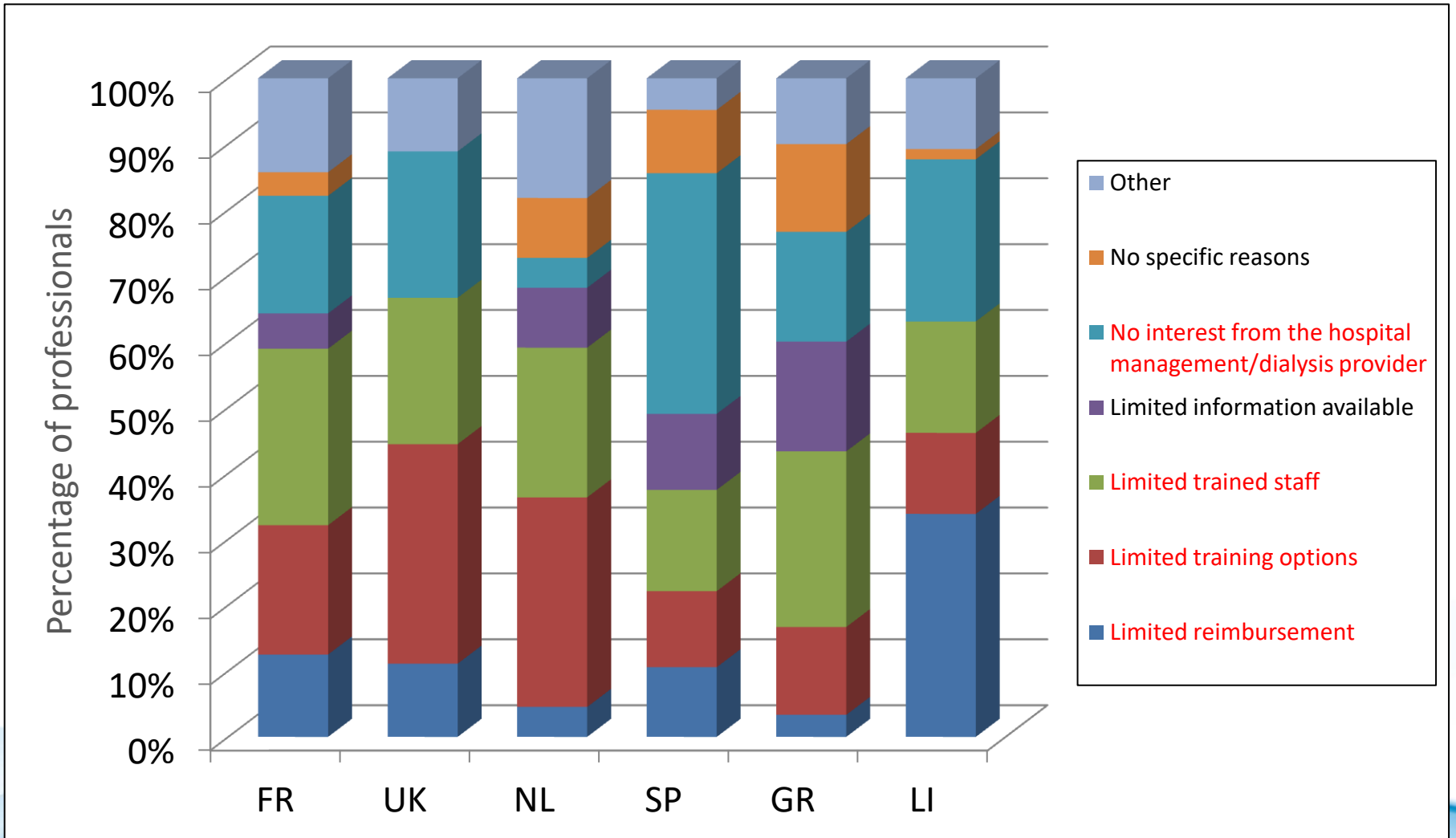
During your time on RRT, have you wanted to change to a different treatment method?



If yes, was your wish to change treatment addressed by your health care professional

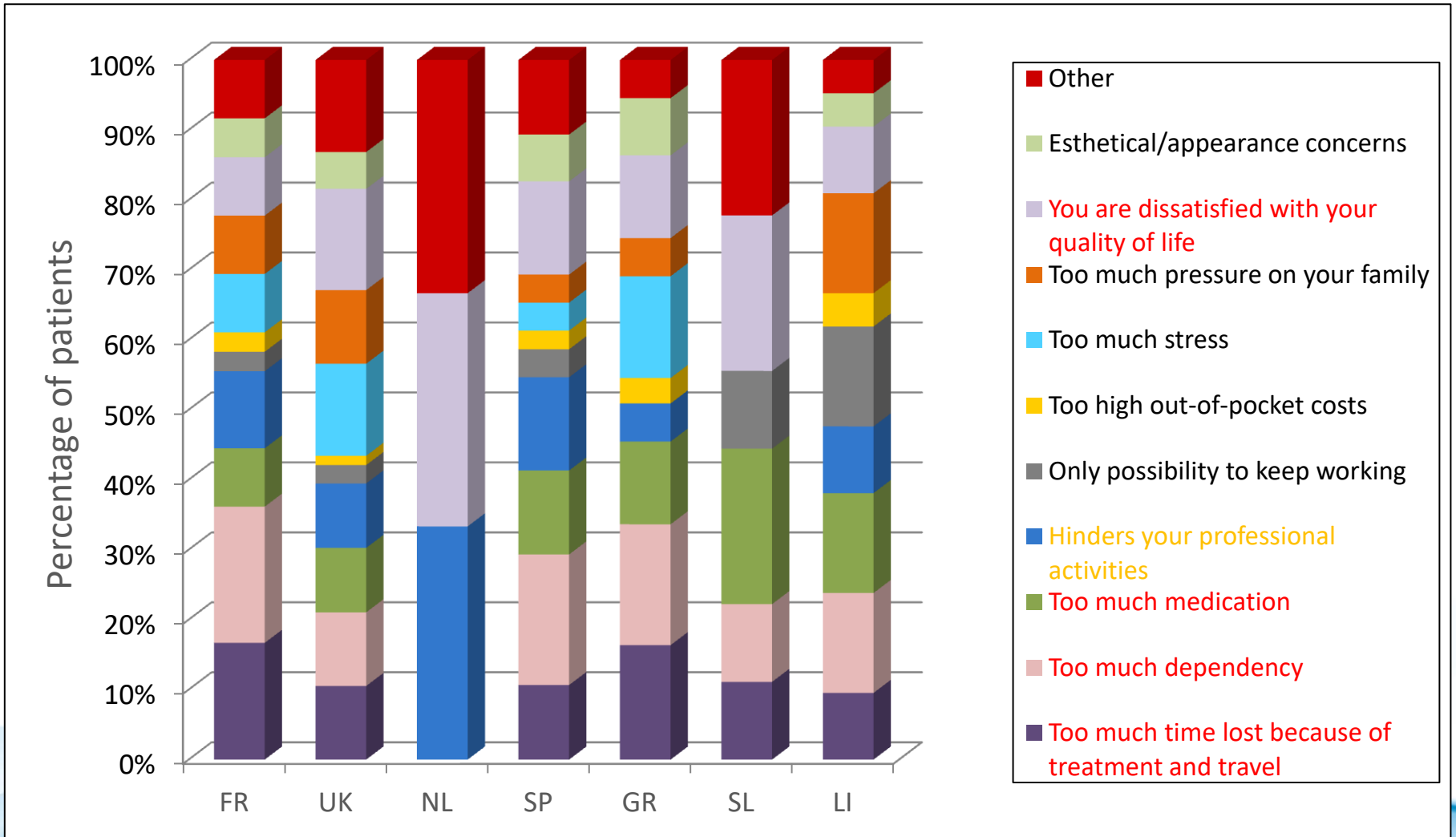


If not, then why?



- Here the slide on the professional status

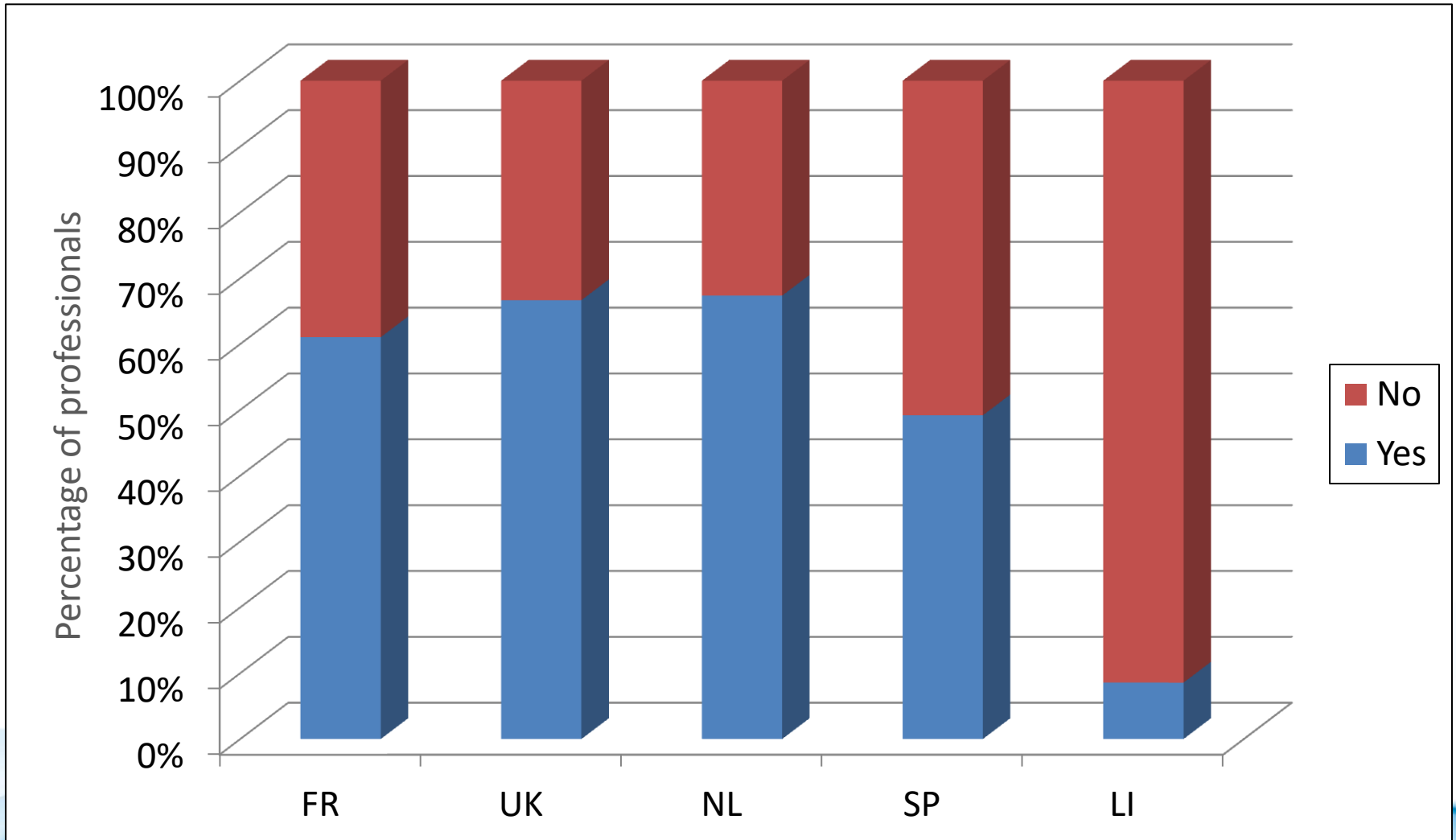
If you have the opinion that your current treatment is not the best option for you, then why?



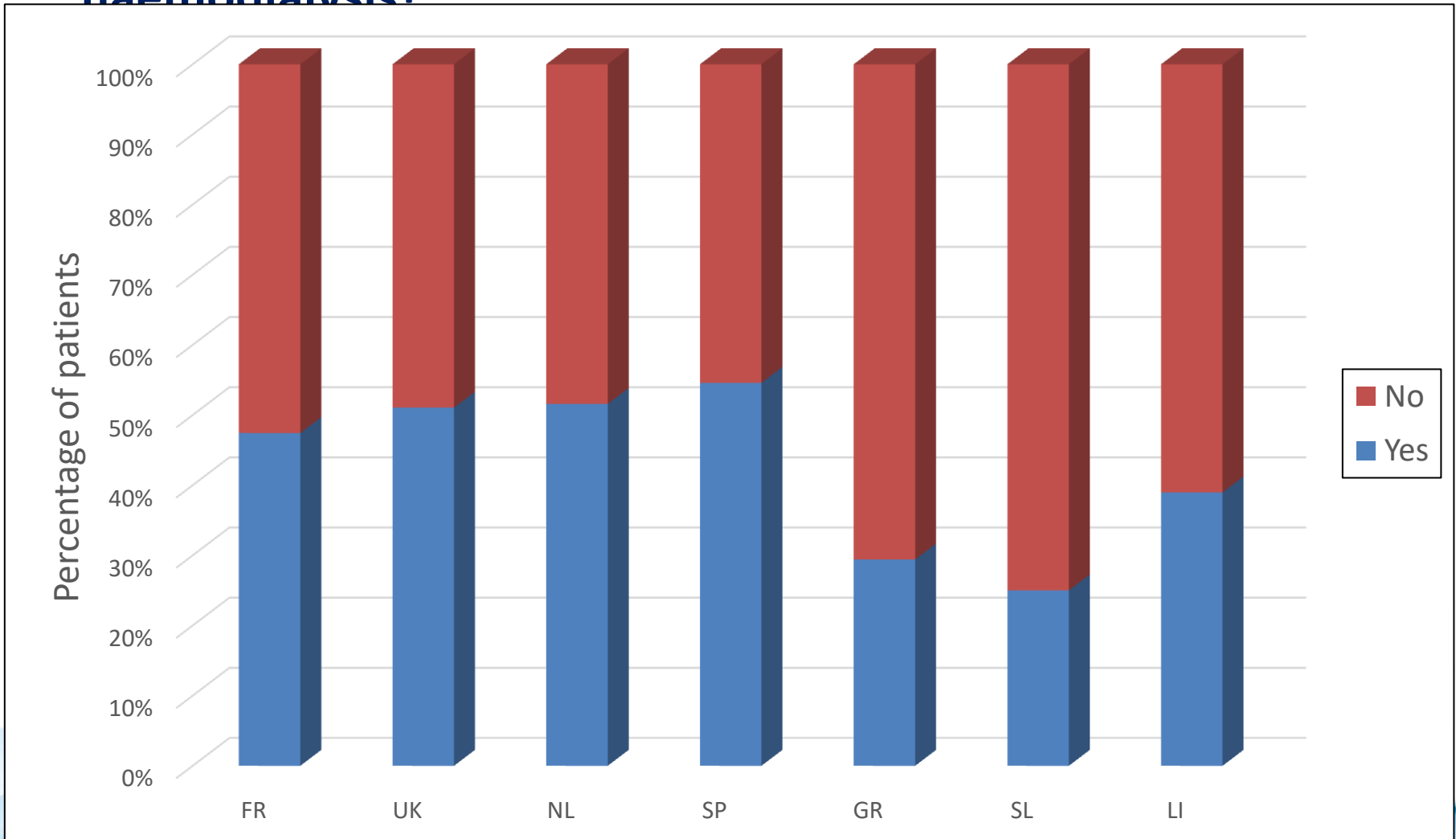
Useful back-ups

In case of extra time

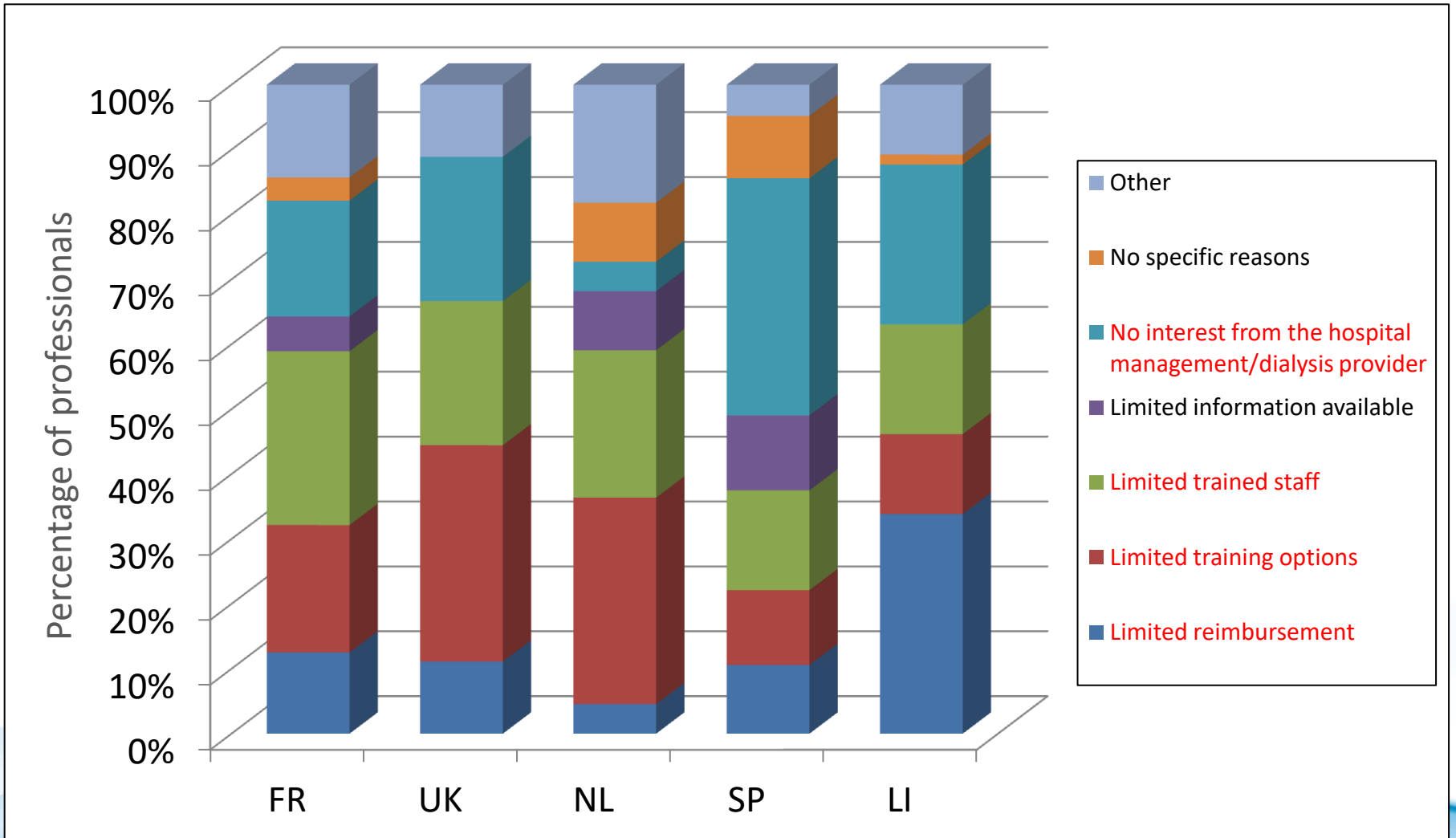
In your centre, is it a standard procedure to offer candidates for RRT information about home haemodialysis?



Patient view: In the period before the start of RRT, do you think you received enough information about home haemodialysis?



If not, then why?



Thanks & Acknowledgments

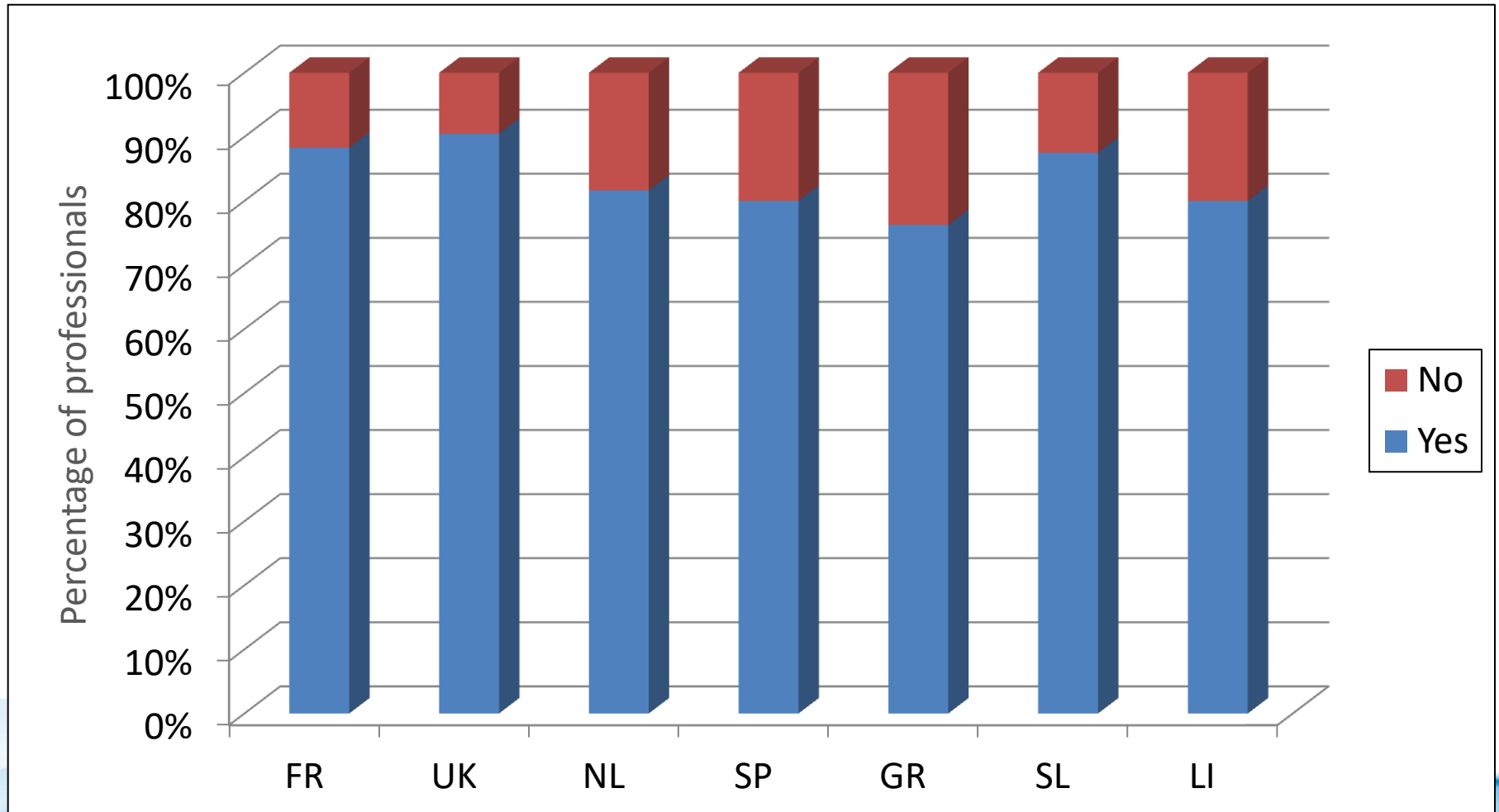
We would like to acknowledge the support received by the following companies by way of an unrestricted educational grant, which helped make this work possible:

Baxter

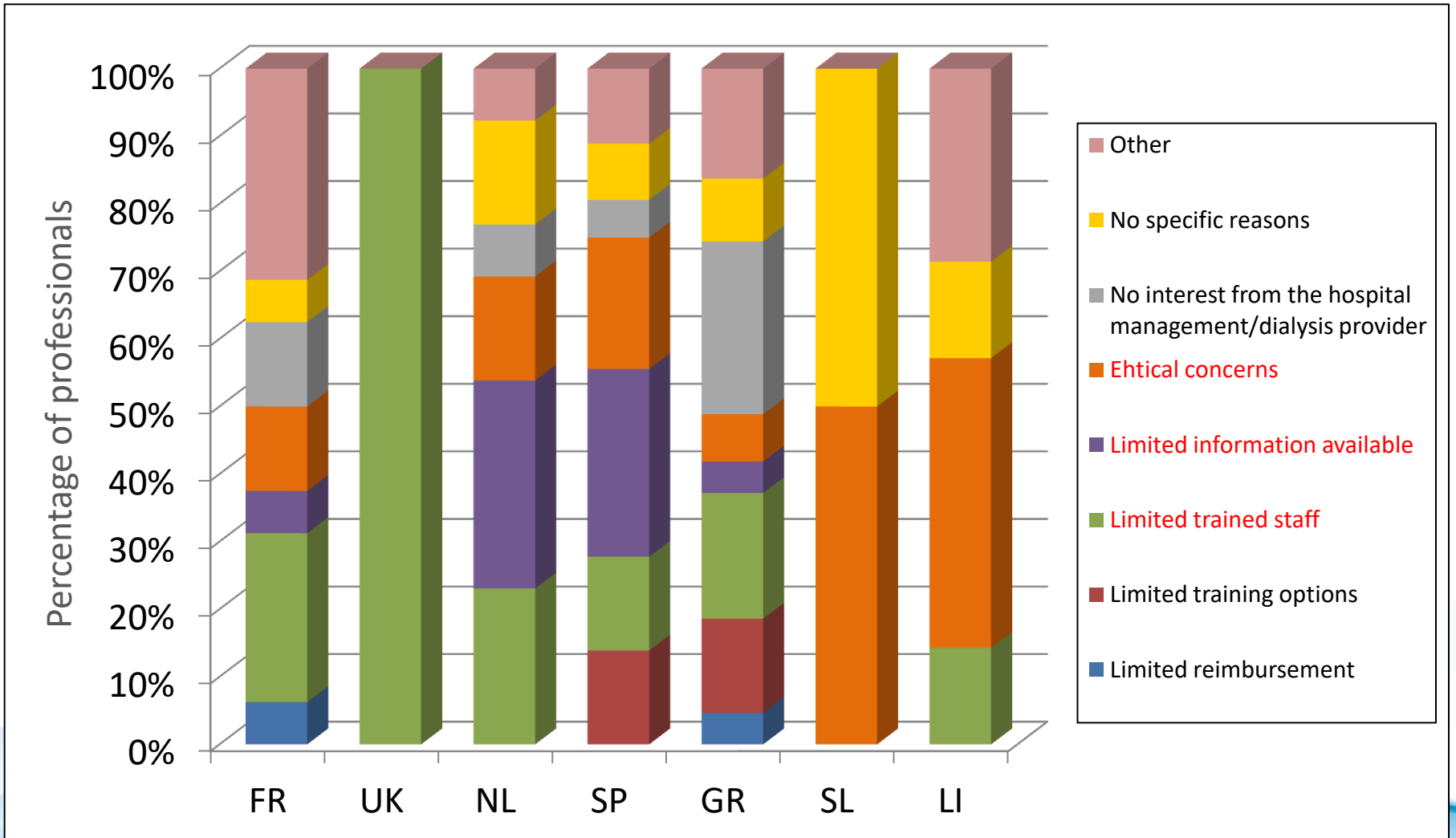
B | BRAUN
SHARING EXPERTISE

AMGEN

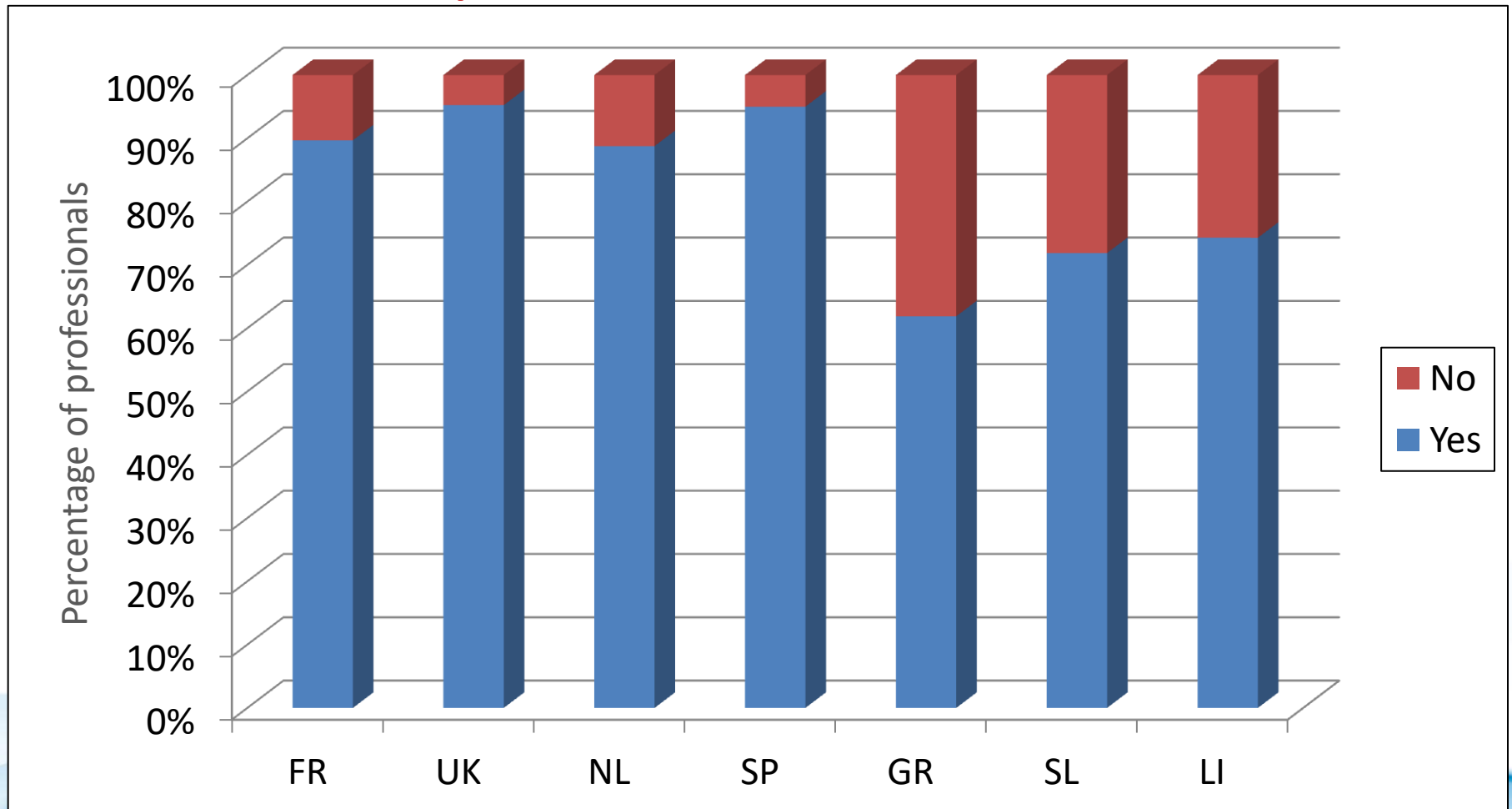
In your centre, is it a standard procedure to offer candidates for RRT information about conservative care?



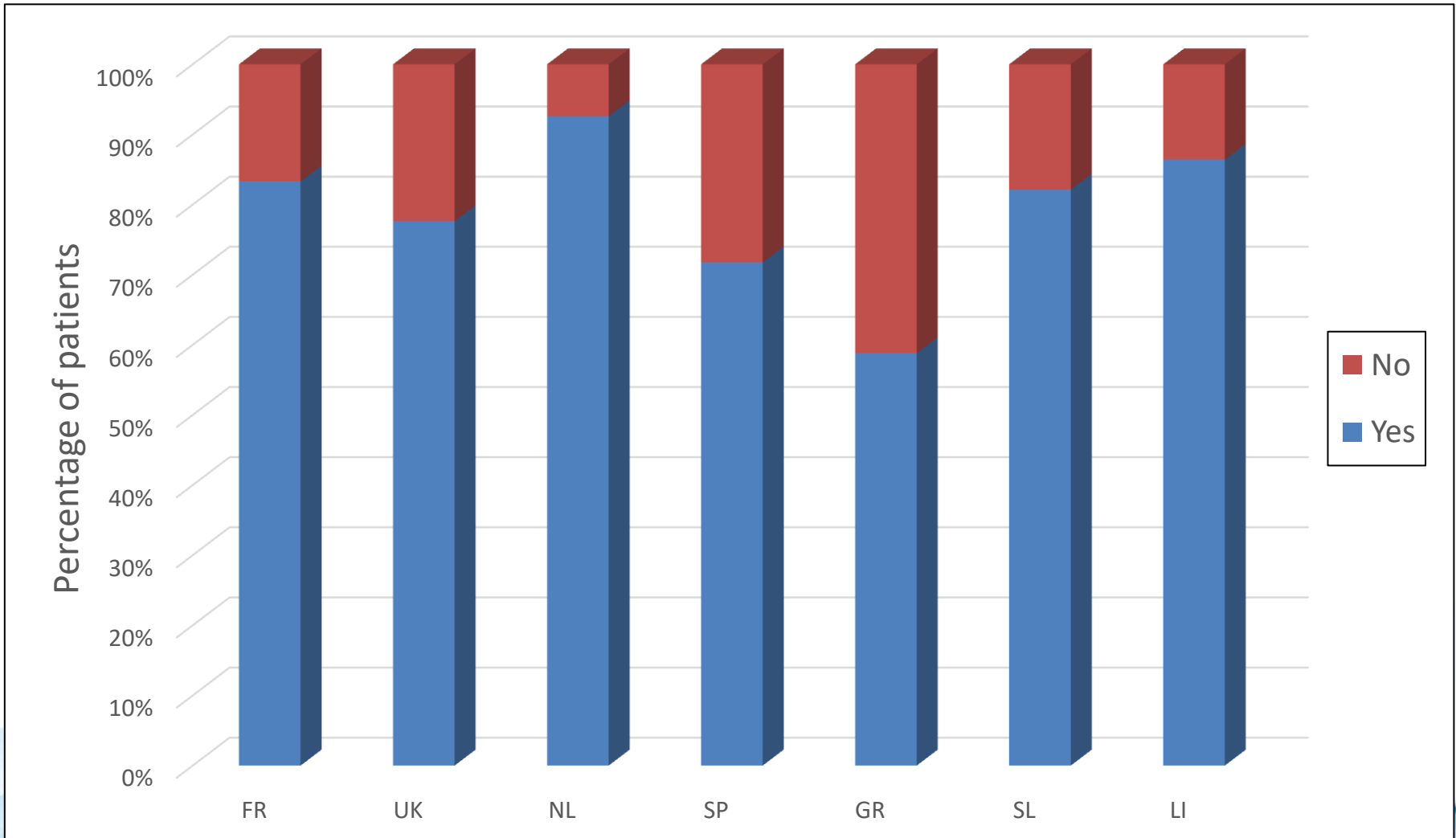
If not, then why?



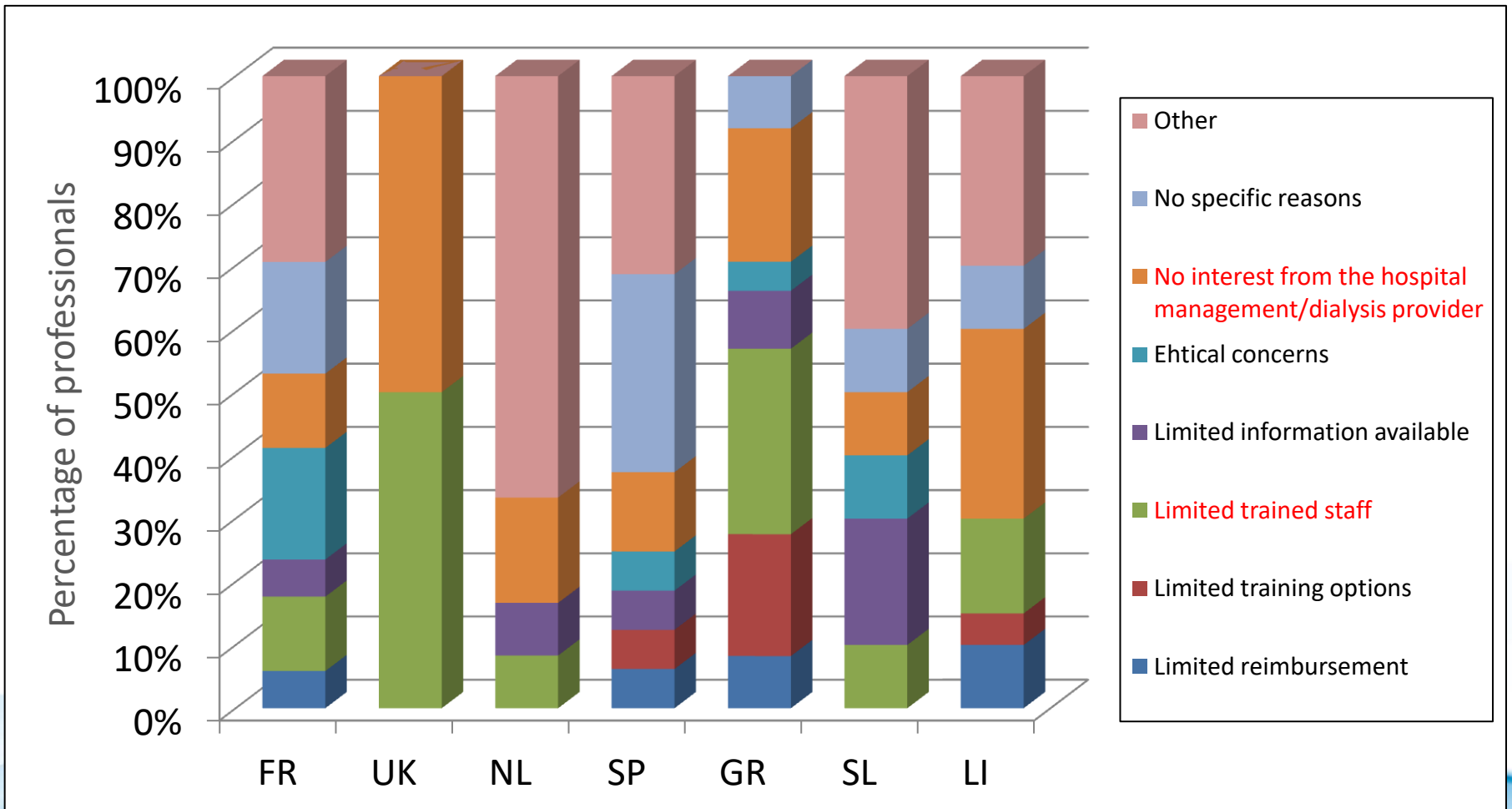
In your centre, is it a standard procedure to offer candidates for RRT information about transplantation (living and deceased donor)?



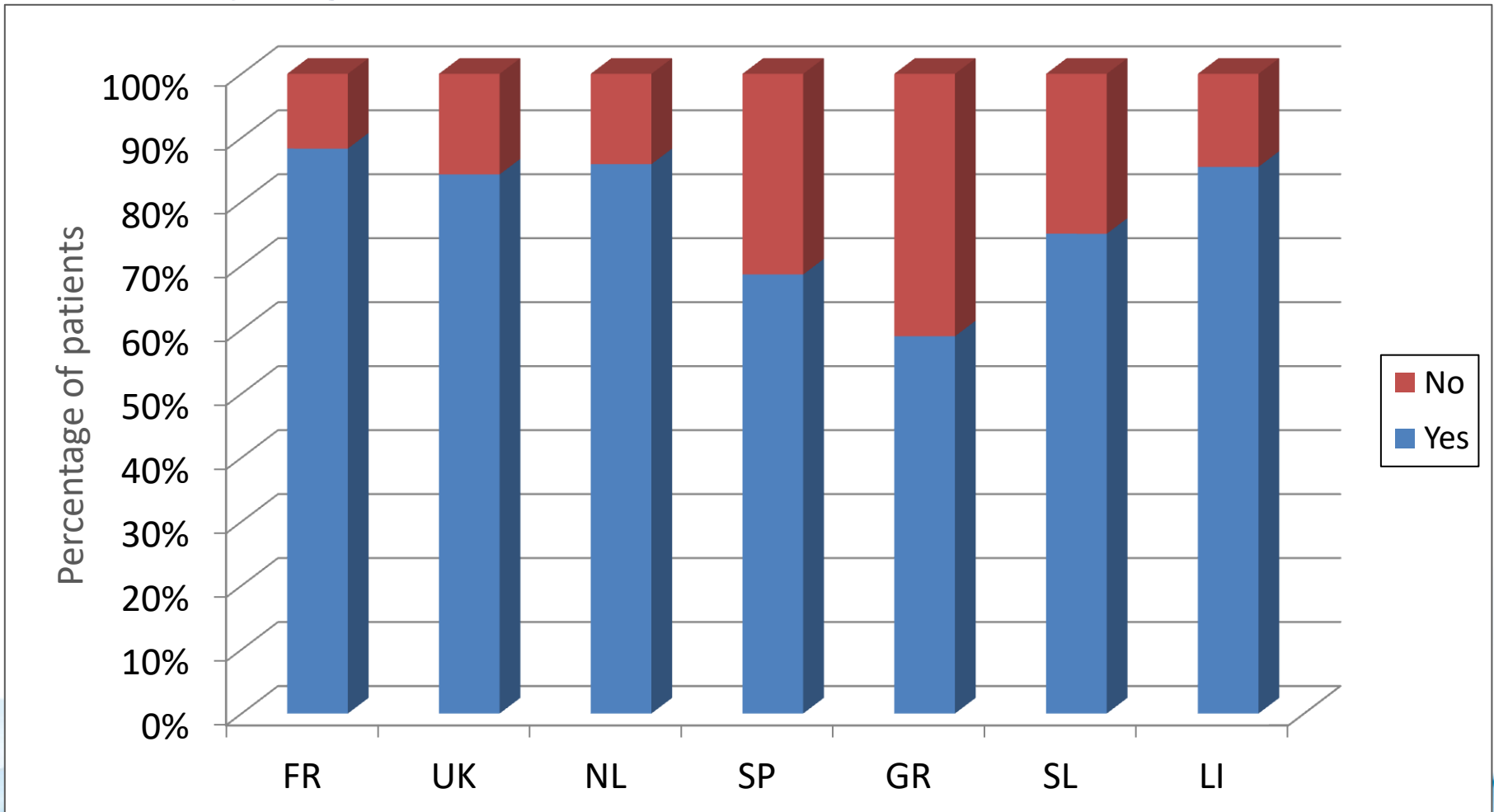
Patient view: Do you think you received enough information about kidney transplantation (living and deceased donor)?



If not, then why?



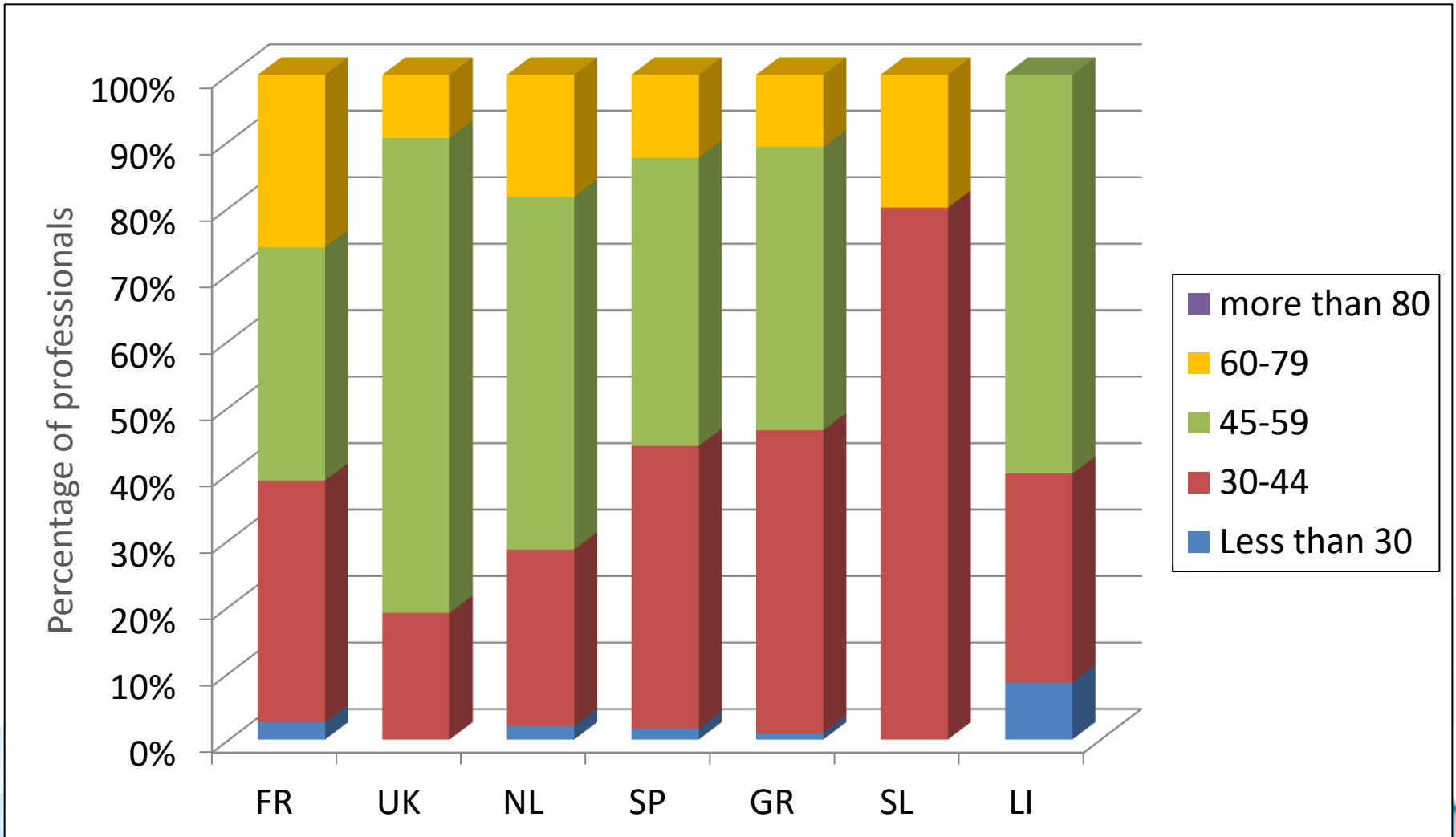
If kidney transplantation was discussed, did you receive information about the possible length of waiting time before a kidney might become available?



Number of answers per gender



Number of answers per age



What issues are we talking about?



What issues are we talking about?

- Inability to continue work or study because of dialysis dependence

What issues are we talking about?

- Inability to continue work or study because of dialysis dependence
- Time lost at dialysis (including traveling to and from and waiting)

What issues are we talking about?

- Inability to continue work or study because of dialysis dependence
- Time lost at dialysis (including traveling to and from and waiting)
- Inability to be mobile/travel

What issues are we talking about?

- Inability to continue work or study because of dialysis dependence
- Time lost at dialysis (including traveling to and from and waiting)
- Inability to be mobile/travel
- Health implications

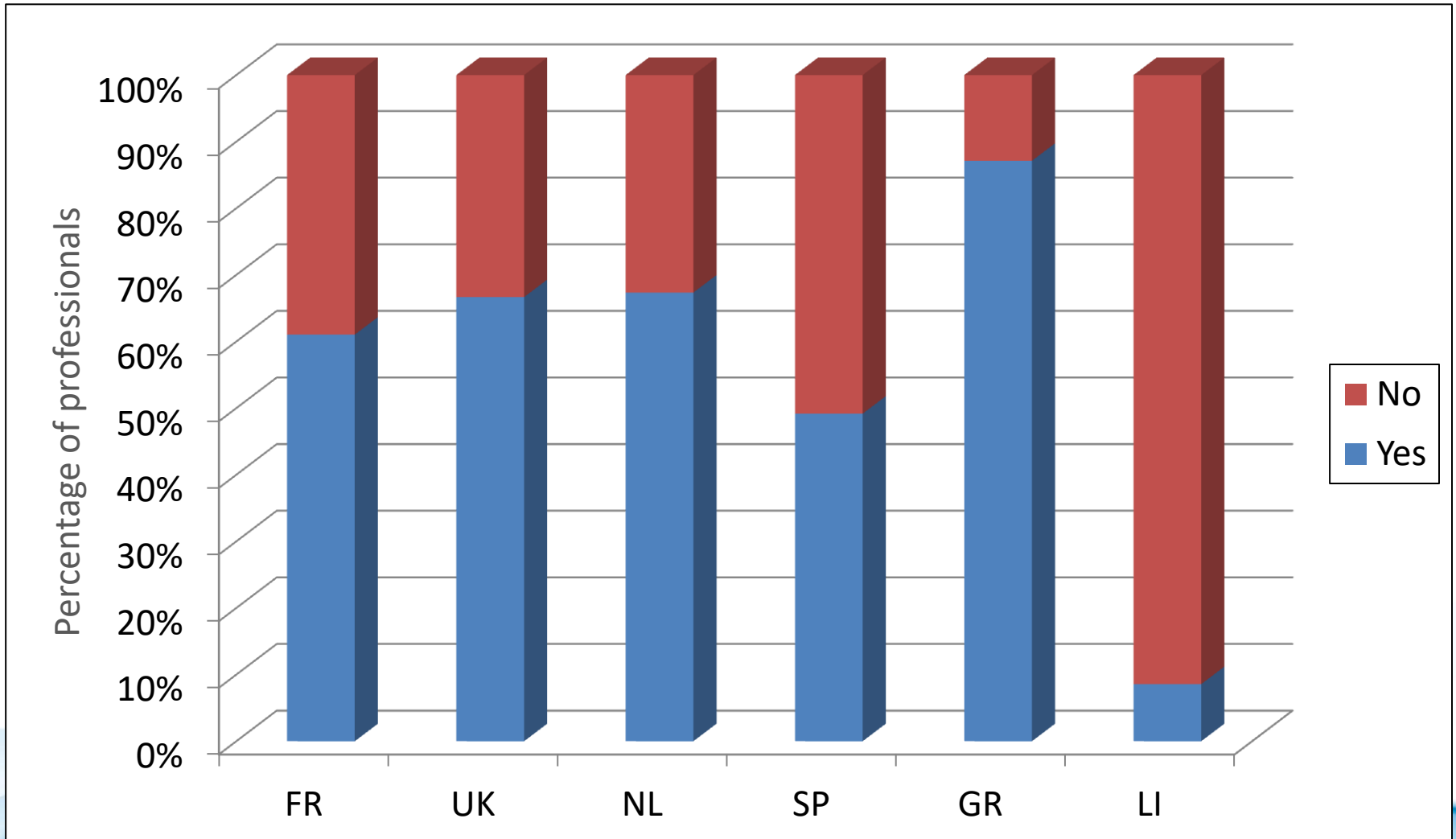
What issues are we talking about?

- Inability to continue work or study because of dialysis dependence
- Time lost at dialysis (including traveling to and from and waiting)
- Inability to be mobile/travel
- Health implications
- Personal cost implications

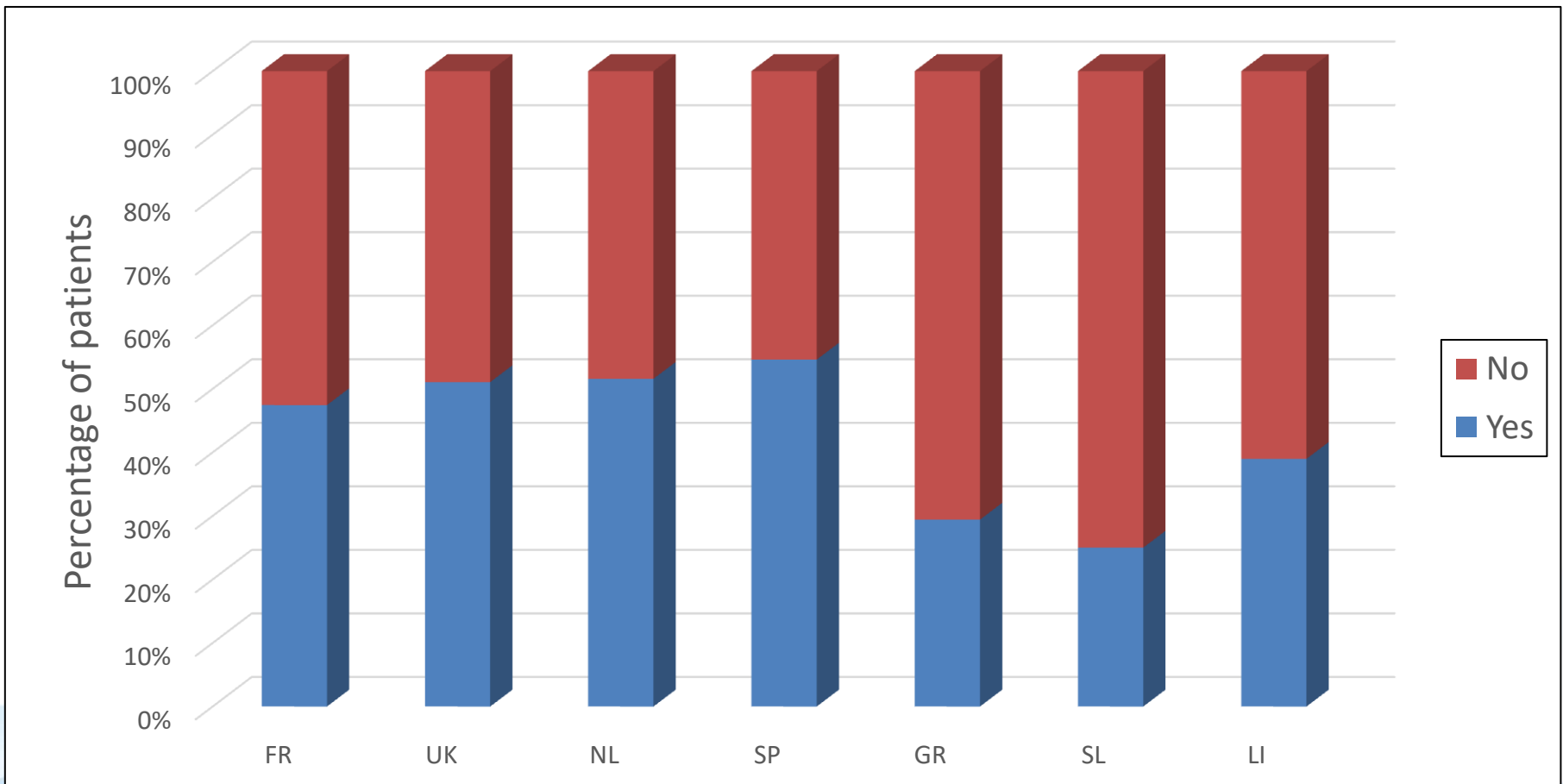
What issues are we talking about?

- Inability to continue work or study because of dialysis dependence
- Time lost at dialysis (including traveling to and from and waiting)
- Inability to be mobile/travel
- Health implications
- Personal cost implications
- Implications for family

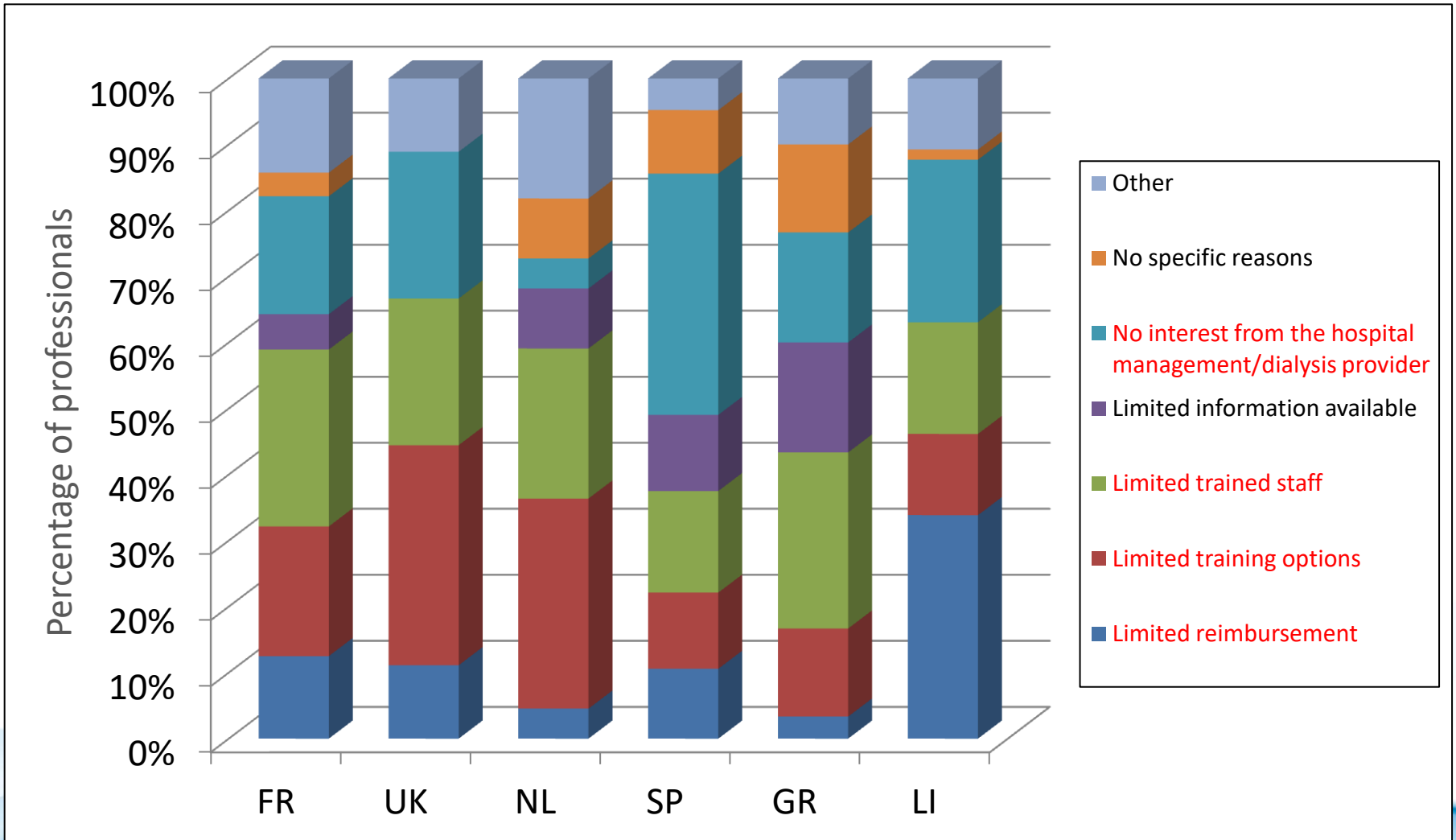
In your centre, is it a standard procedure to offer candidates for RRT information about home haemodialysis?



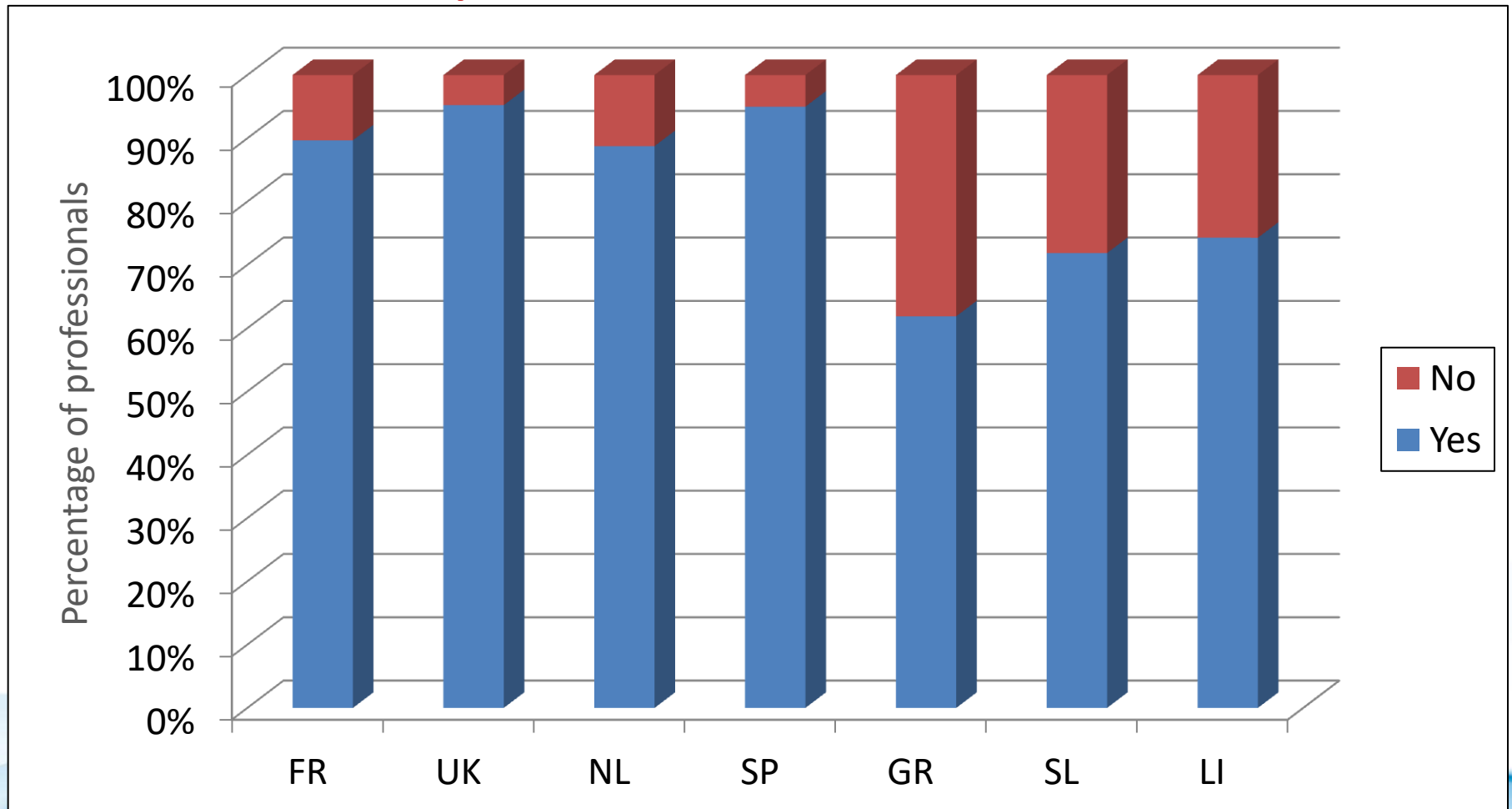
Patient view: In the period before the start of RRT, do you think you received enough information about home haemodialysis?



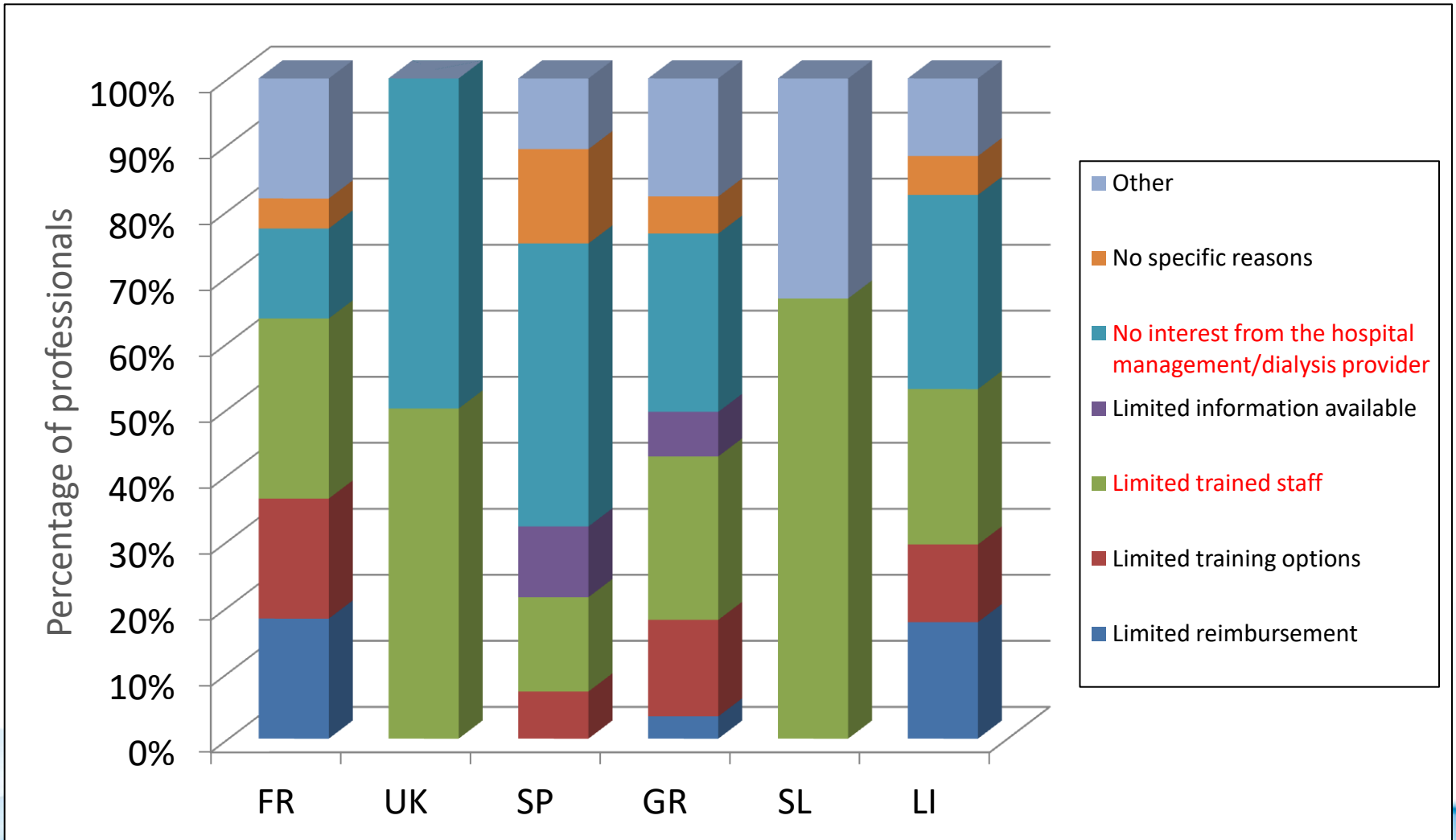
In your centre, is it a standard procedure to offer candidates for RRT information about home haemodialysis? - if no, why?



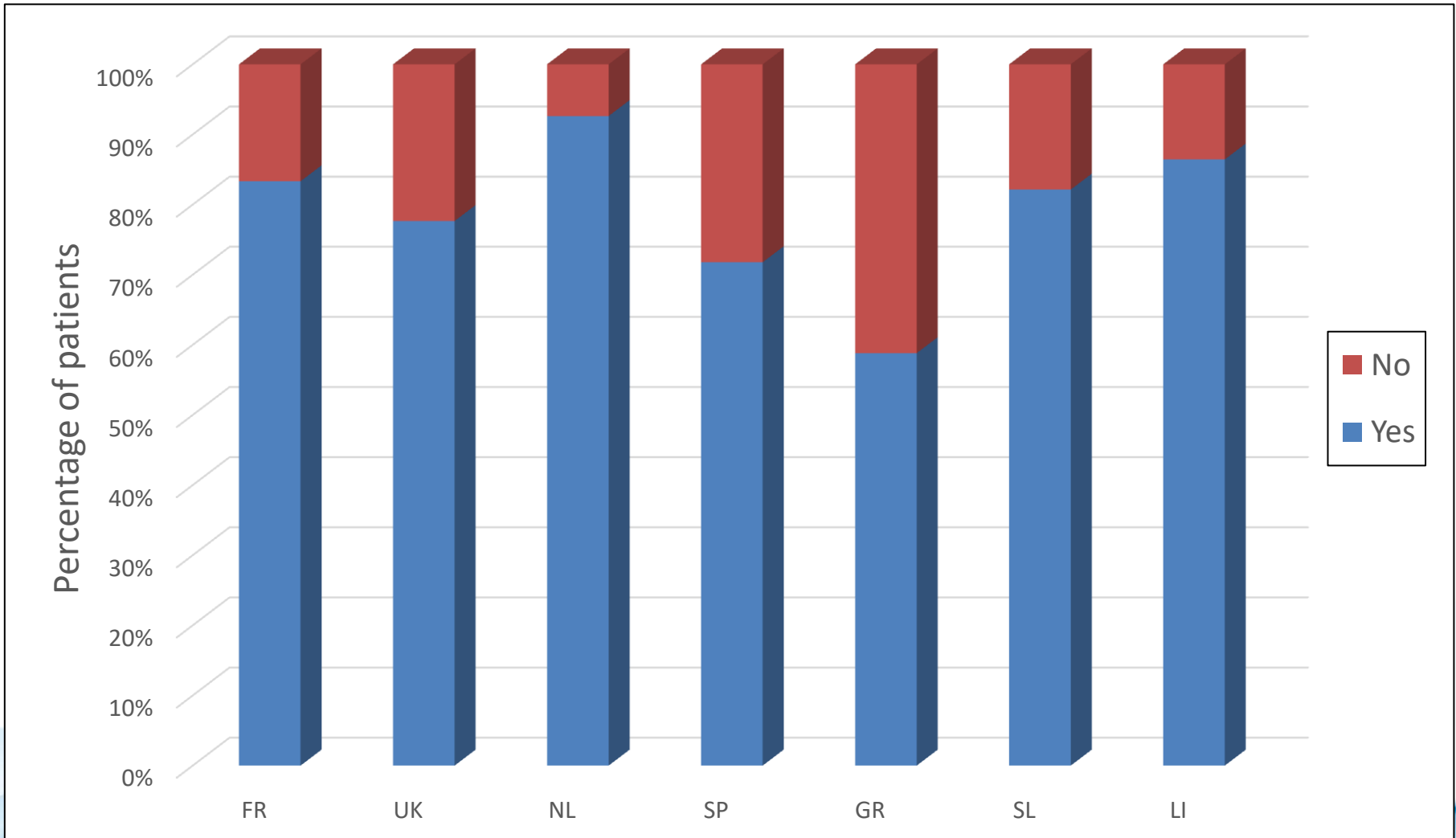
In your centre, is it a standard procedure to offer candidates for RRT information about transplantation (living and deceased donor)?



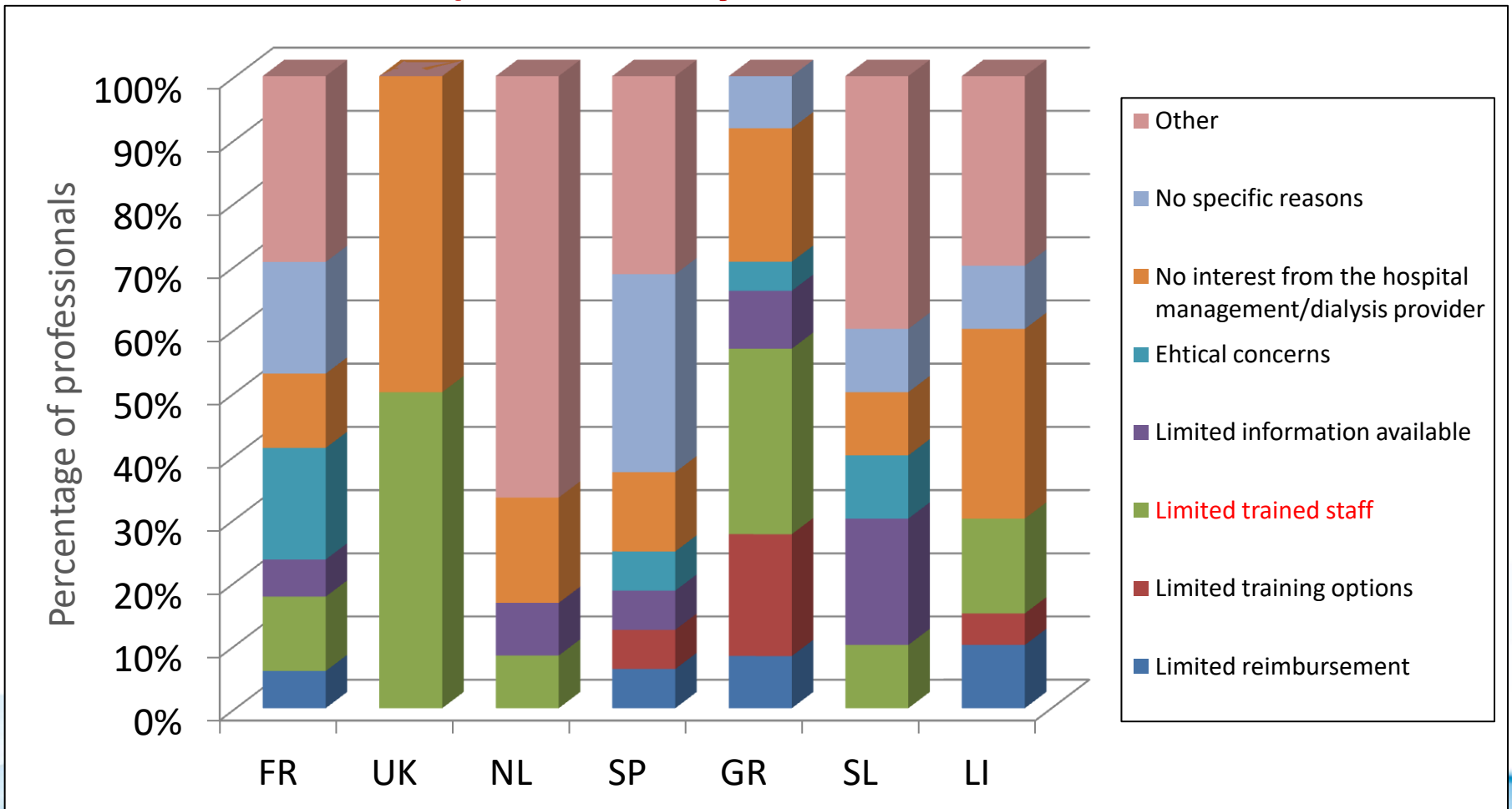
In your centre, is it a standard procedure to offer candidates for RRT information about transplantation? - if no, why?



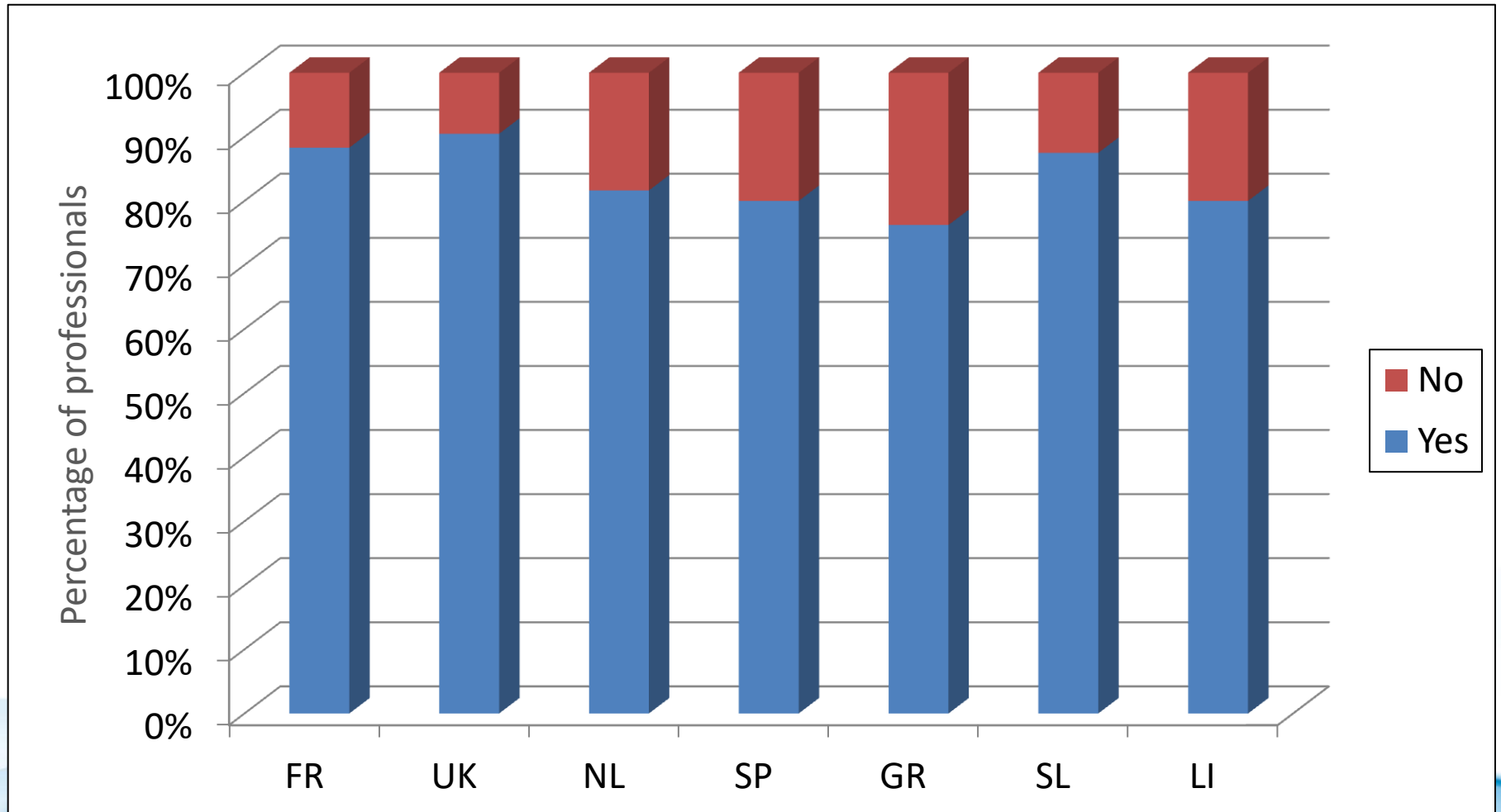
Patient view: Do you think you received enough information about kidney transplantation (living and deceased donor)?



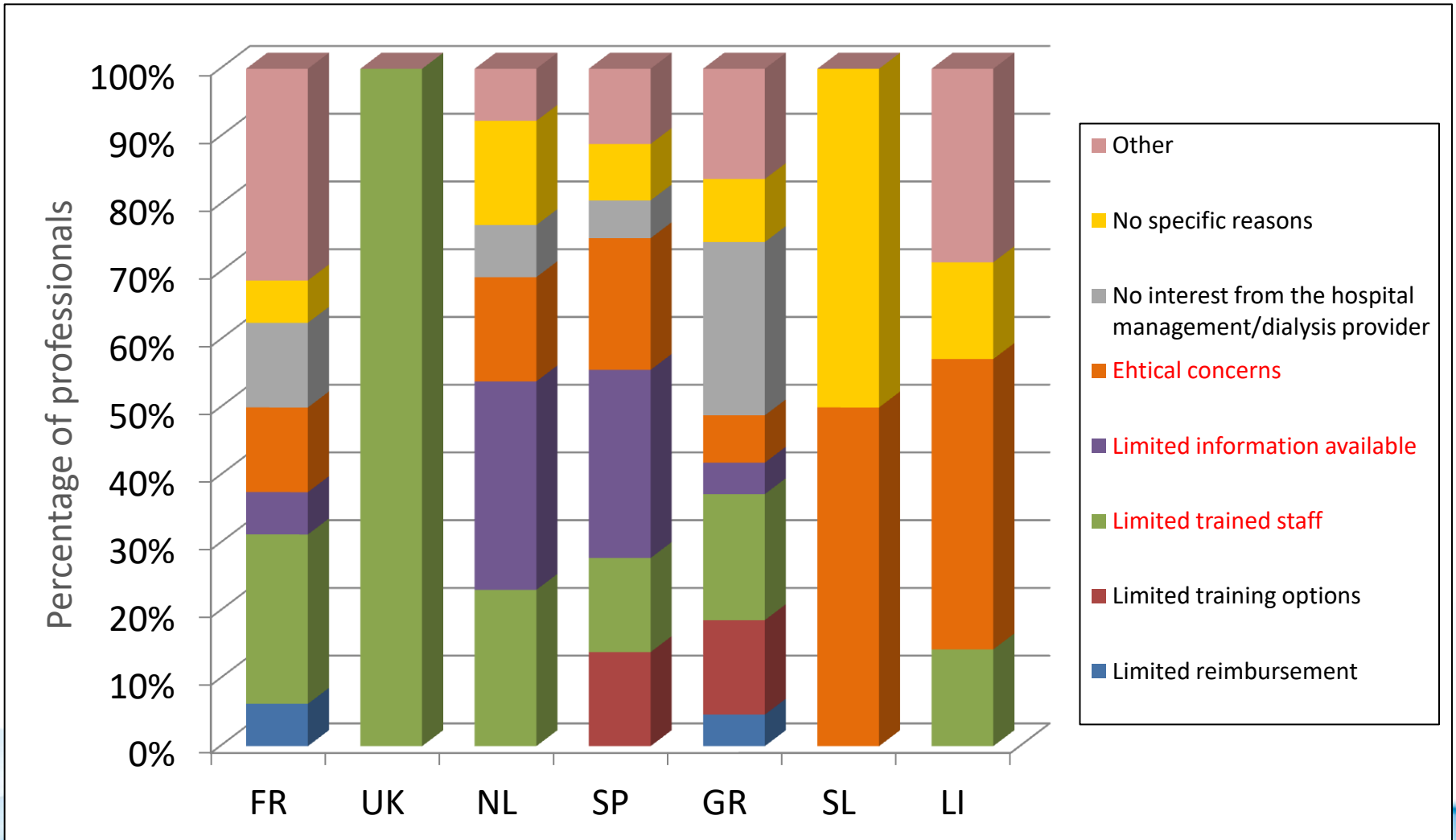
In your centre, is it a standard procedure to offer candidates for RRT information about transplantation (living and deceased donor) - if no, why?



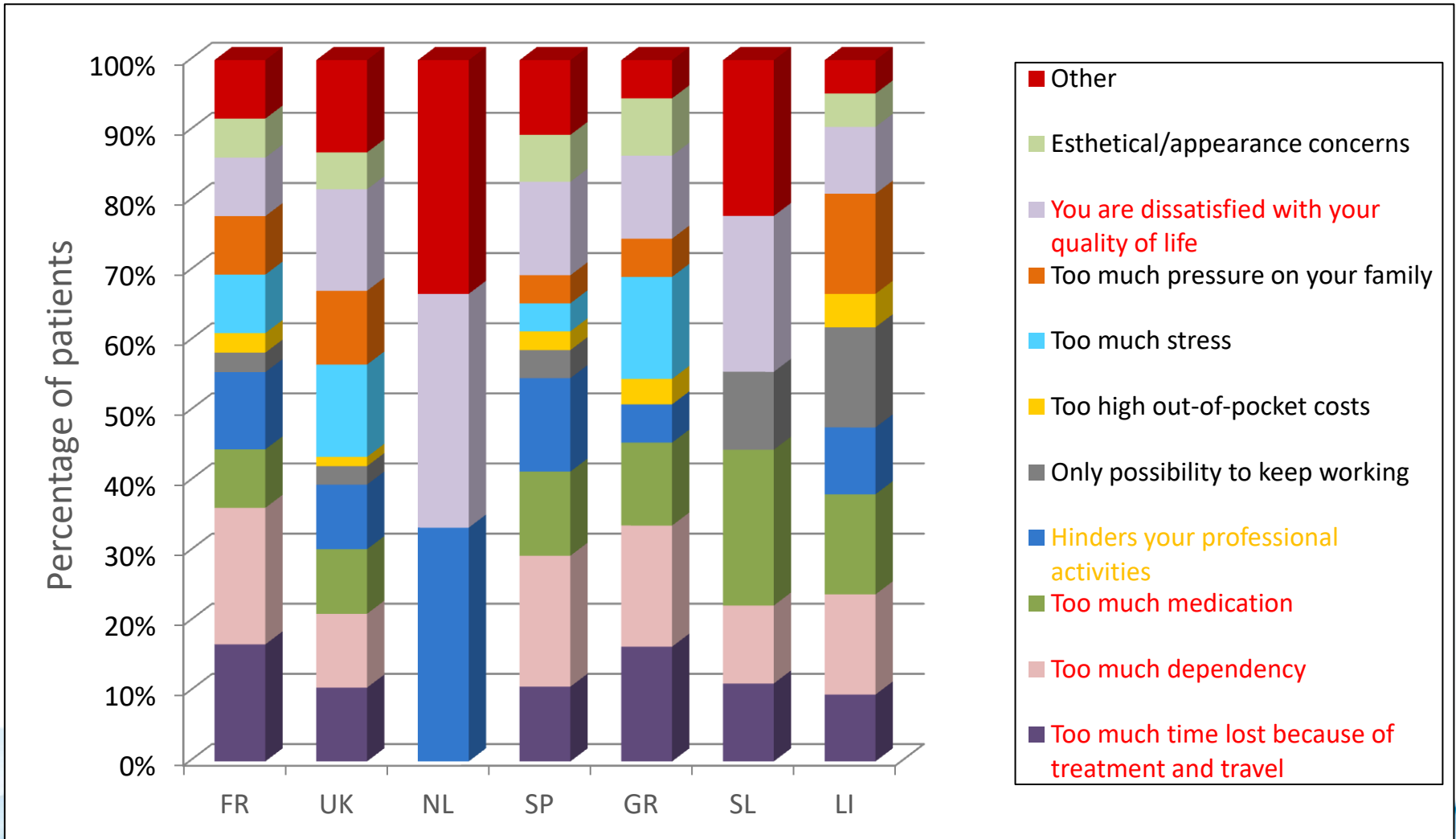
In your centre, is it a standard procedure to offer candidates for RRT information about conservative care?



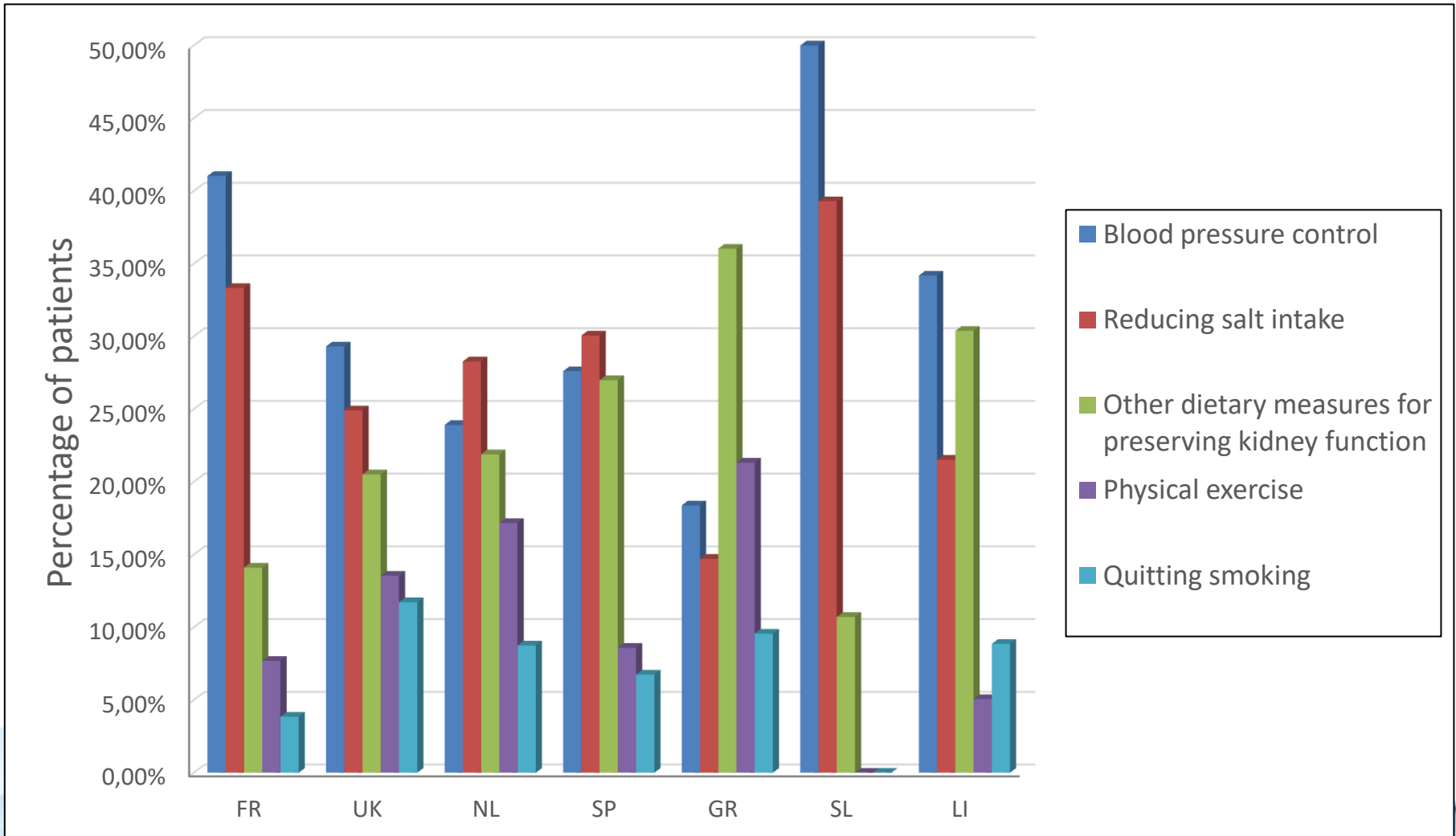
In your centre, is it a standard procedure to offer candidates for RRT information about conservative care - if no, why?



Is you have the opinion that your current treatment is not the best option for you, then why?



In the time before the start of RRT, did you receive information on any of the following?



In the period before the start of RRT, was the option of conservative care discussed with you?

