

Registo da IRCT



Sociedade Portuguesa de Pediatria
Secção de Nefrologia Pediátrica

Conceição Mota
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Registo de dialise e transplante



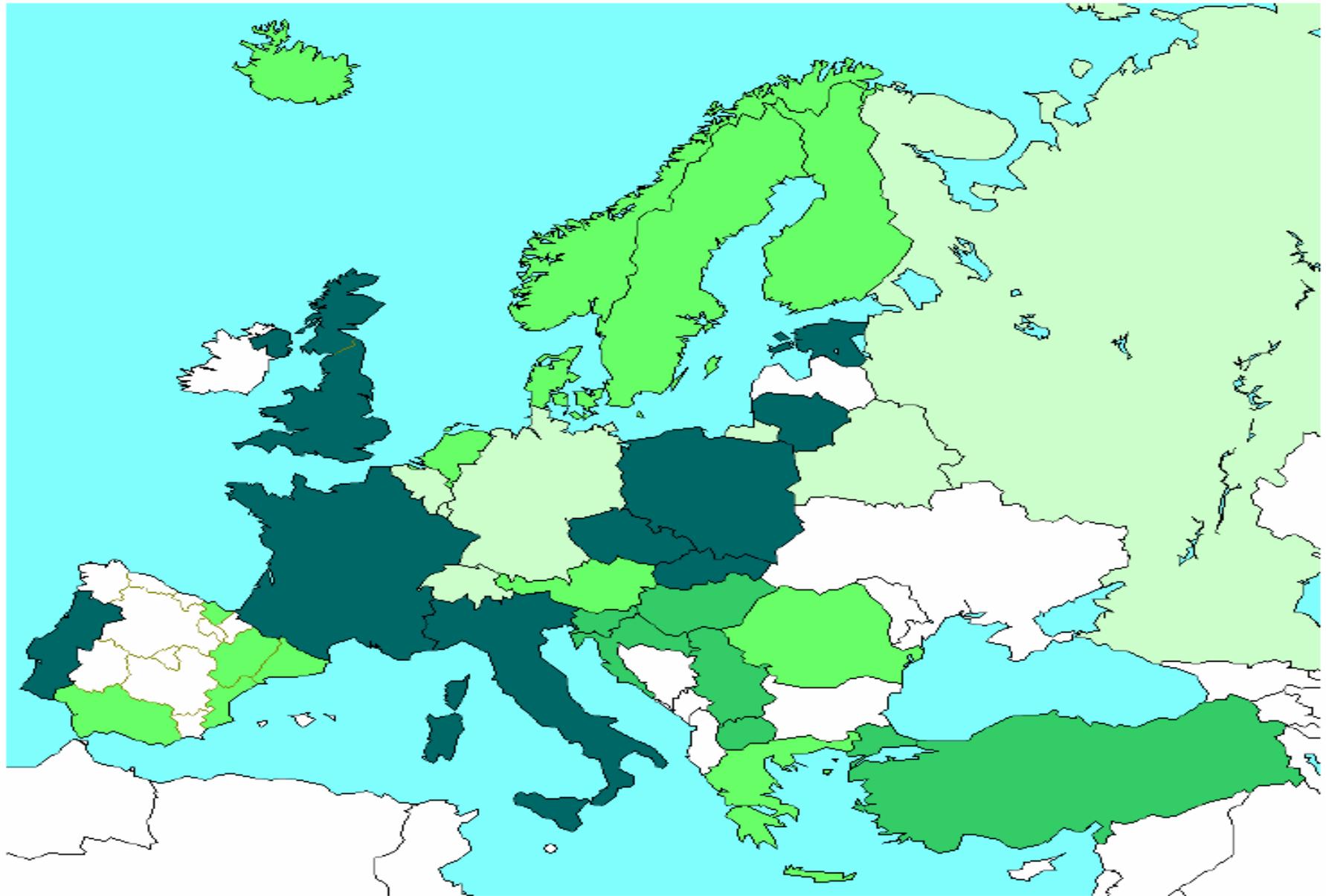
Sociedade Portuguesa de Pediatria
Secção de Nefrologia Pediátrica

- **Objectivo:** Registo dos doentes em tratamento substitutivo renal (TSR) .
- **2006:** Início do registo.
- **2008:** Integração do registo da ESPN

Base de dados: Informação obrigatória

- Código do doente
- Sexo
- Data de nascimento
- Etiologia
- Data e tipo do 1ª TSR

- Evento: Alteração para DP, HD, TR, morte, recuperação da função renal, transferência para outro Centro e perda de “follow-up”
- Data do evento.



Provided extended data to the ESPN Registry

Provided limited data to the ESPN Registry

Provided data via the ERA-EDTA Registry

Intend to contribute data in the near future

Baseline Characteristics, provide at start renal replacement therapy (RRT)

Step 1. Essential information, required.

provide essential information for baseline data obtained at the first day (day 1)

Patient identifier	<input type="text" value="example"/>	please, provide a unique patient identifier that stays the same over the years, for a list of e
Gender	<input type="text" value="M"/>	
Date of birth (dd/mm/yyyy)	<input type="text" value="17-01-1988"/>	
Primary renal disease code	<input type="text" value="Haemolytic Uraemic Syndrome (including Moschcowitz Syndrome)"/>	
Date of first RRT (dd/mm/yyyy)	<input type="text" value="10-01-1990"/>	
Treatment at start of RRT	<input type="text" value="transplantation"/>	OR ERA-EDTA treatment code: <input type="text"/>
New on RRT/from other center	<input type="text" value="patient starting RRT"/>	

Step 2a Extended A (high priority data collection) PROVIDE AT DAY 1

please - provide available extended A data obtained at day 1

Comorbidity yes/no	<input type="text" value="yes"/>
if yes:comorbidity 1	<input type="text" value="congenital cardiovascular disease"/>
if yes:comorbidity 2	<input type="text"/>
if yes:comorbidity 3	<input type="text"/>
if yes:comorbidity other (in English)	<input type="text"/>
Height (cm)	<input type="text" value="100,00"/>
Weight (kg)	<input type="text" value="20,00"/>
Serum creatinine levels	<input type="text" value="7,00"/> <input type="text" value="mg/dl"/>

Extended data specific for EITHER transplantation

Step 3a. transplantation information. Provide data regarding day 1 (click)	EITHER - provide via trans
Step 3b. dialysis information. Provide data regarding day 90 (click)	- provide around c

Events: death, changes of treatment modality, recovery of renal function and transfer out

[data c](#)

Essential information (required)

Patient identifier

example

For a list of patients with baseline characteristics [click here](#) [search existing patient IDs](#)

baseline patient information

- date of birth

17/Jan/88

- sex

M

- date first RRT

10-01-1990

New event

Save record

Date of change treatment

12-10-1996

Event

Change to PD

OR

ERA-EDTA treatment code

[coding - treatment modalities+ events](#)

Cause of Death

[coding - COD \(ERA-EDTA codes\)](#)

Extended A data (high priority data collection)

Cause of graft failure

Cause of dialysis failure

Dialysis event /follow-up

Transplantation event

Transplantation follow-up

Table 1: Incident Patients

Incident paediatric patients accepted for renal replacement therapy in 2006 and general population characteristics of all the countries contributing data to the ESPN Registry.

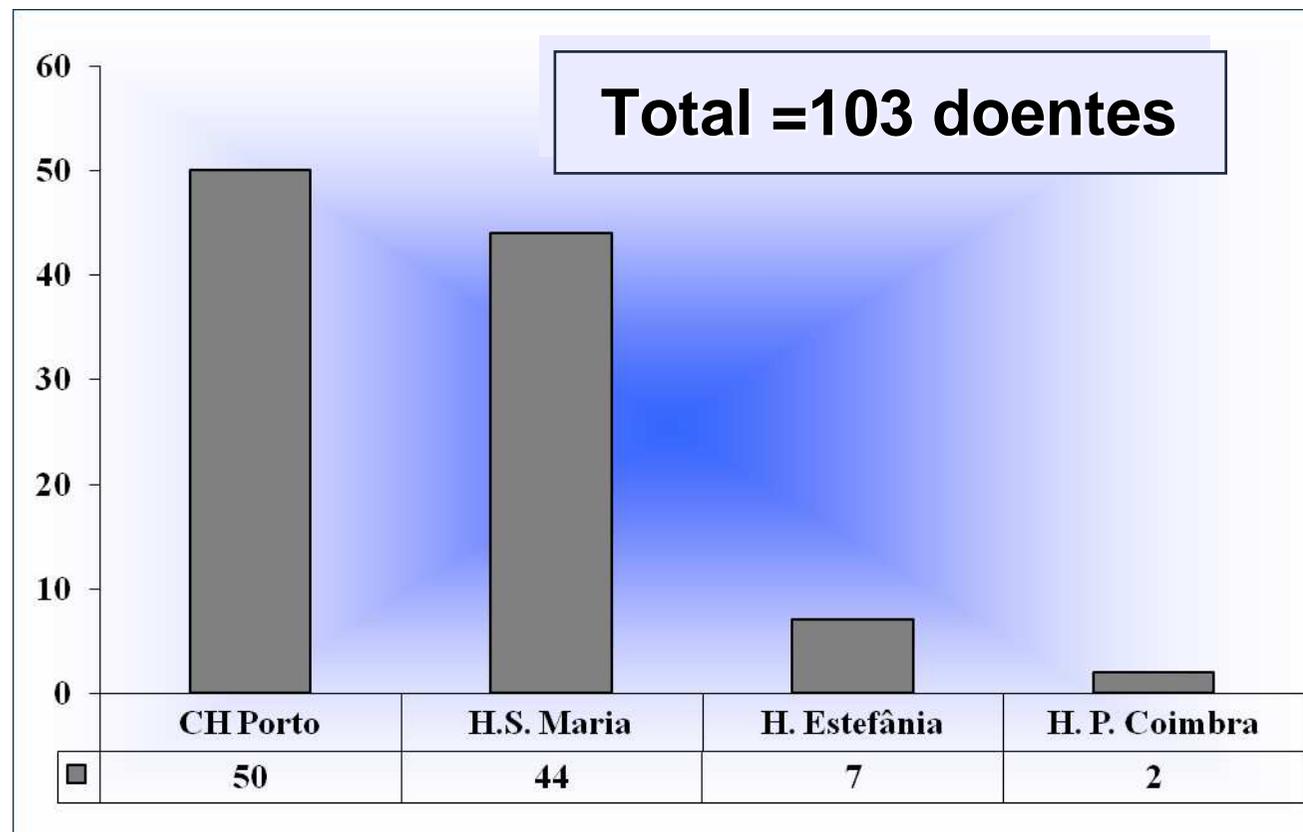
Country	Total	General Population Characteristics		
	RRT patients 0-15 [count]	children 0-15 [count]	all 0-99 [count]	children 0-15 [%]
Austria	9	1,312,978	8,267,906	15.9
Czech Republic	10	1,490,425	10,269,147	14.5
Denmark	8	1,015,017	5,437,281	18.7
Finland	6	904,045	5,266,278	17.2
France *	40	11,738,421	63,195,466	18.6
FYR of Macedonia	0	391,301	2,039,375	19.2
Greece	6	1,595,018	11,148,465	14.3
Hungaria ^{us}	8	1,325,733	8,661,386	15.3
Iceland	0	65,411	303,789	21.5
Italy *	48	8,303,033	58,941,509	14.1
Lithuania	7	549,260	3,394,091	16.2
Norway	5	906,374	4,660,687	19.4
Poland	27	6,105,769	38,141,274	16.0
Portugal	11	1,640,936	10,584,353	15.5
Romania	16	3,339,093	21,587,680	15.5
Serbia	0	1,157,618	7,411,576	15.6
Slovenia	0	282,151	2,006,876	14.1
Spain, Andalusia	6	1,286,895	7,848,514	16.4
Spain, Aragon	0	163,168	1,277,471	12.8
Spain, Basque country	4	262,830	2,133,684	12.3
Spain, Catalonia ^z	10	988,016	6,995,206	14.1
Spain, Valencia	7	694,452	4,806,908	14.4
Sweden	21	1,555,182	9,080,513	17.1
the Netherlands	26	2,971,601	16,346,112	18.2
Turkey * ^y	113	40,895,172	142,275,515	28.7
United Kingdom *	61	11,609,490	65,665,800	17.7
Total	449	102,549,389	517,746,862	19.8

Table 2: Prevalent Patients

Prevalence of renal replacement therapy in paediatric patients in 2006. Prevalent counts and prevalence per million age related population, by age and gender.

Country	Total		Age Groups			Gender	
	RRT patients 0-15		infants 0-4	children 5-9	youngsters 10-15	men 0-15	women 0-15
	[count]	[pmp]	[pmp]	[pmp]	[pmp]	[pmp]	[pmp]
Austria	51	38.8	22.5	42.0	49.5	43.1	34.4
Czech Republic	28	18.8	12.3	17.8	25.2	19.6	17.9
Denmark	41	40.4	12.3	38.5	68.2	51.9	28.3
Finland	80	88.5	66.3	103.0	95.0	101.9	74.5
France *	193	16.4	14.0	14.3	21.2	17.8	15.0
FYR of Macedonia	4	10.2	0.0	23.6	6.7	14.9	5.3
Greece	44	27.6	7.6	33.1	41.7	38.2	24.5
Hungaria [§]	37	27.9	7.3	19.1	52.7	38.2	17.0
Iceland	3	45.9	0.0	46.8	87.8	30.0	62.4
Italy *	278	33.5	21.0	33.7	45.6	39.4	27.3
Lithuania	15	27.3	13.2	17.1	44.9	28.4	26.2
Norway	45	49.6	31.2	36.2	79.7	62.4	36.2
Poland	102	16.7	17.9	18.0	14.8	21.4	11.8
Portugal	54	32.9	18.2	33.1	47.5	38.0	27.5
Romania	33	9.9	0.9	7.2	20.4	7.6	12.3
Serbia	6	5.2	5.3	5.5	4.8	8.4	1.8
Slovenia	6	21.3	22.2	21.8	20.0	34.5	7.3
Spain, Andalusia	42	32.6	6.9	43.4	48.2	33.3	32.0
Spain, Aragon	4	24.5	18.1	0.0	54.7	23.9	25.2
Spain, Basque country	18	68.5	31.3	81.6	98.5	66.6	70.4
Spain, Catalonia [‡]	56	56.7	30.7	63.2	79.9	74.7	37.5
Spain, Valencia	28	40.3	25.2	31.2	64.7	53.2	26.7
Sweden	77	49.5	29.7	47.0	68.7	52.7	46.2
the Netherlands	124	41.7	15.3	39.9	69.6	48.0	35.1
Turkey * [†]	487	11.9	2.4	10.0	23.6	11.9	11.9
United Kingdom *	519	44.7	15.4	39.9	76.2	55.0	33.7
Total	2375	23.2	10.8	21.4	36.9	26.4	19.7

Nº doentes registados ano de 2007



Dados dos doentes

Sexo M/F: 64/39

Raça branca/negra/outra: 88/13/2

(31/12/2007):

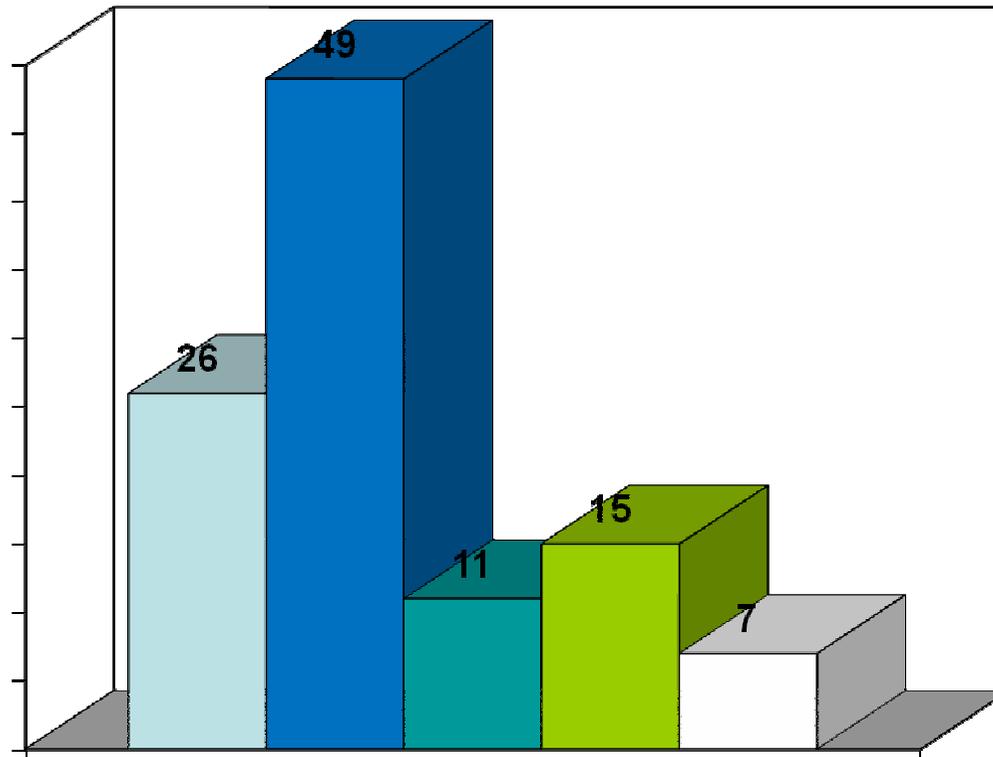
Mínimo: 3 meses; Máximo: 18,7 anos

Idade média = $11,7 \pm 5,1$ anos

Idade mediana -12,7 anos

Idade	<15 anos	>=15anos
Nº de doentes	59	43

Etiologia da IRC



□ Glomerulopatias

■ Uropatia obstrutiva e/ou pielonefrite e/ou displasia/hipoplasia renal

■ Doenças vasculares / sistêmicas

■ Doenças hereditárias

□ Etiologia desconhecida

Comorbilidade

Síndrome malformativo múltiplo- 7	Anomalia cromossómica-1
D. Cardiovascular congénita- 5	D.Pulmonar crónica-3
D.Hepática crónica-7	AIDS-HIV-1
D. neurológica-8	Atraso de desenvolvimento-11

Idade início da TSR

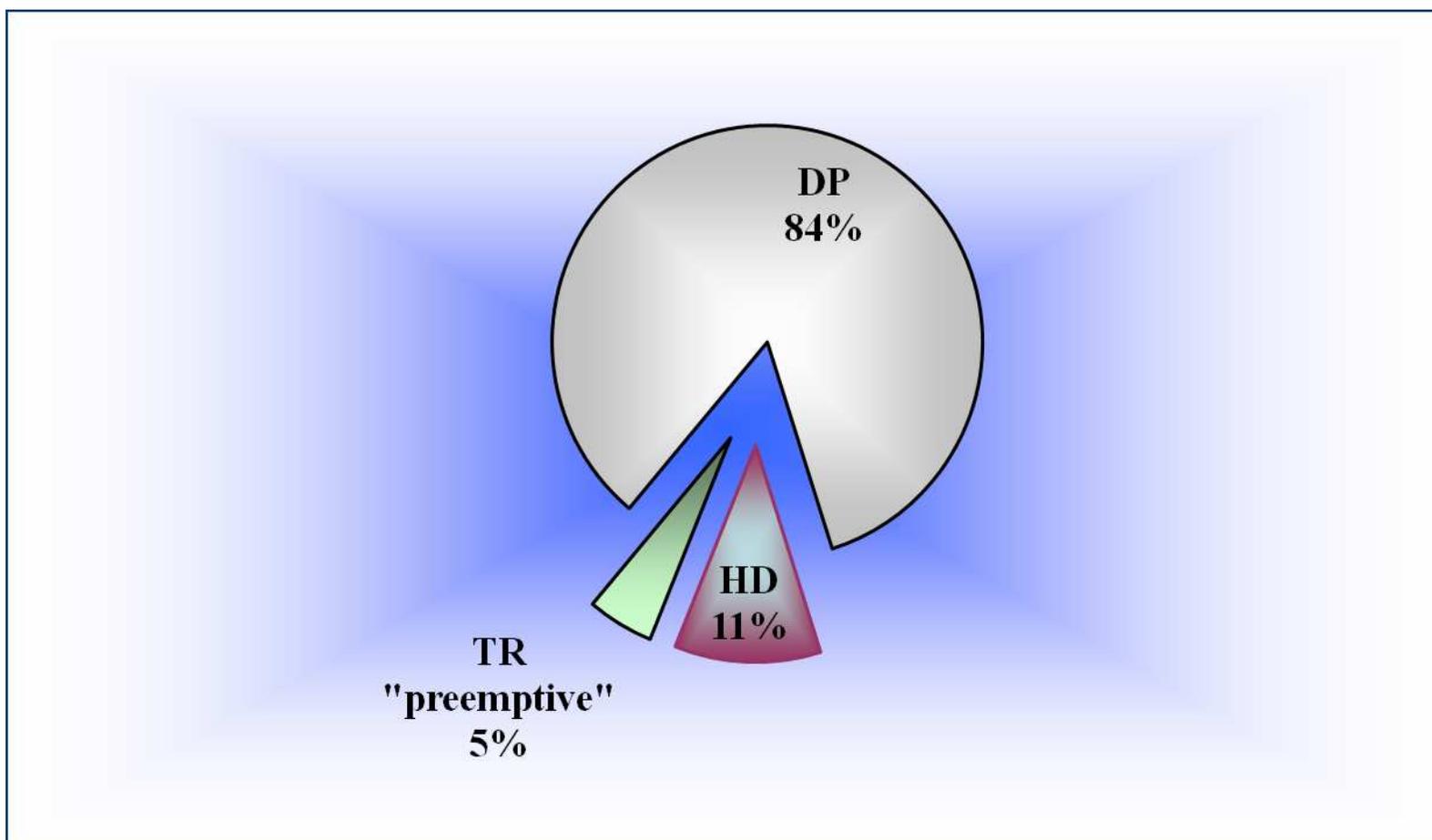
- Idade média=7,9 ± 5,0 anos
- Mínimo: D1 vida: Máximo: 17 anos

Idade	Nº (%)
<1 ano	18*(17,4%)
≥1 e < 12 anos	58 (56,3%)
≥ 12 anos	26 (25,2%)

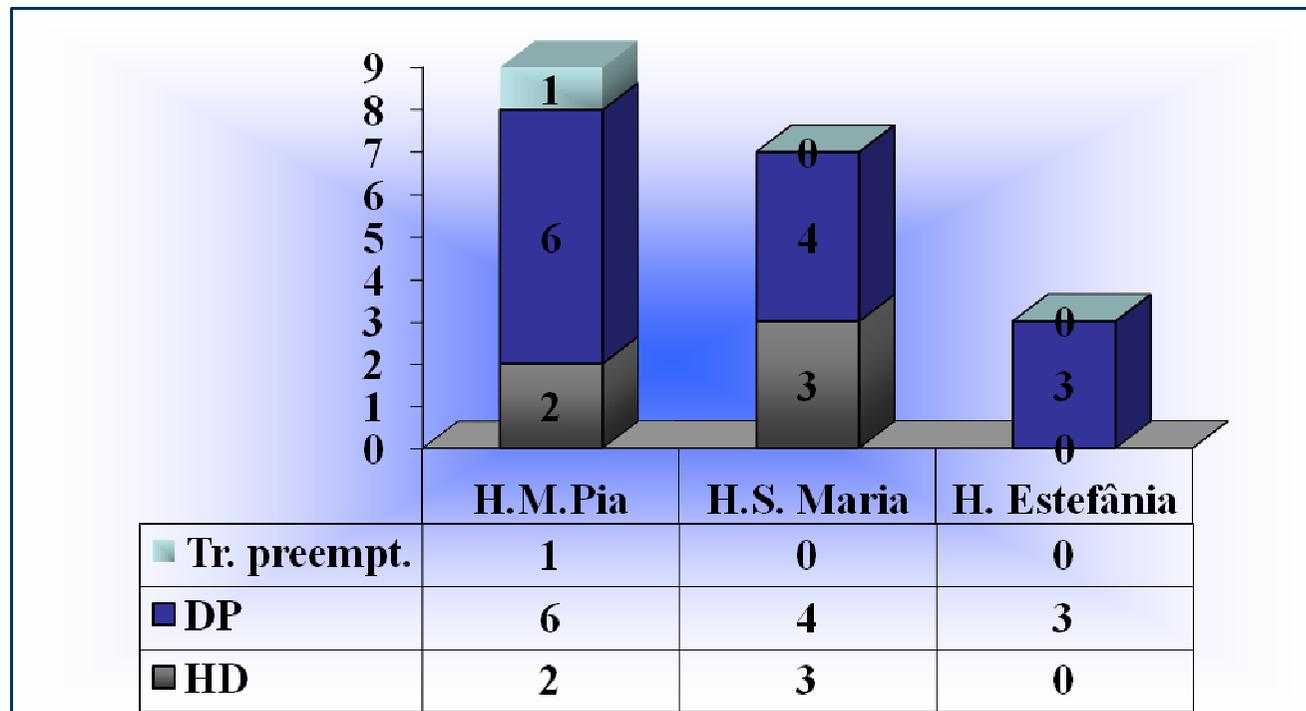
* 7 iniciaram em recém-nascidos

Terapêutica substitutiva renal (D1)

N=103



Novos doentes no ano de 2007



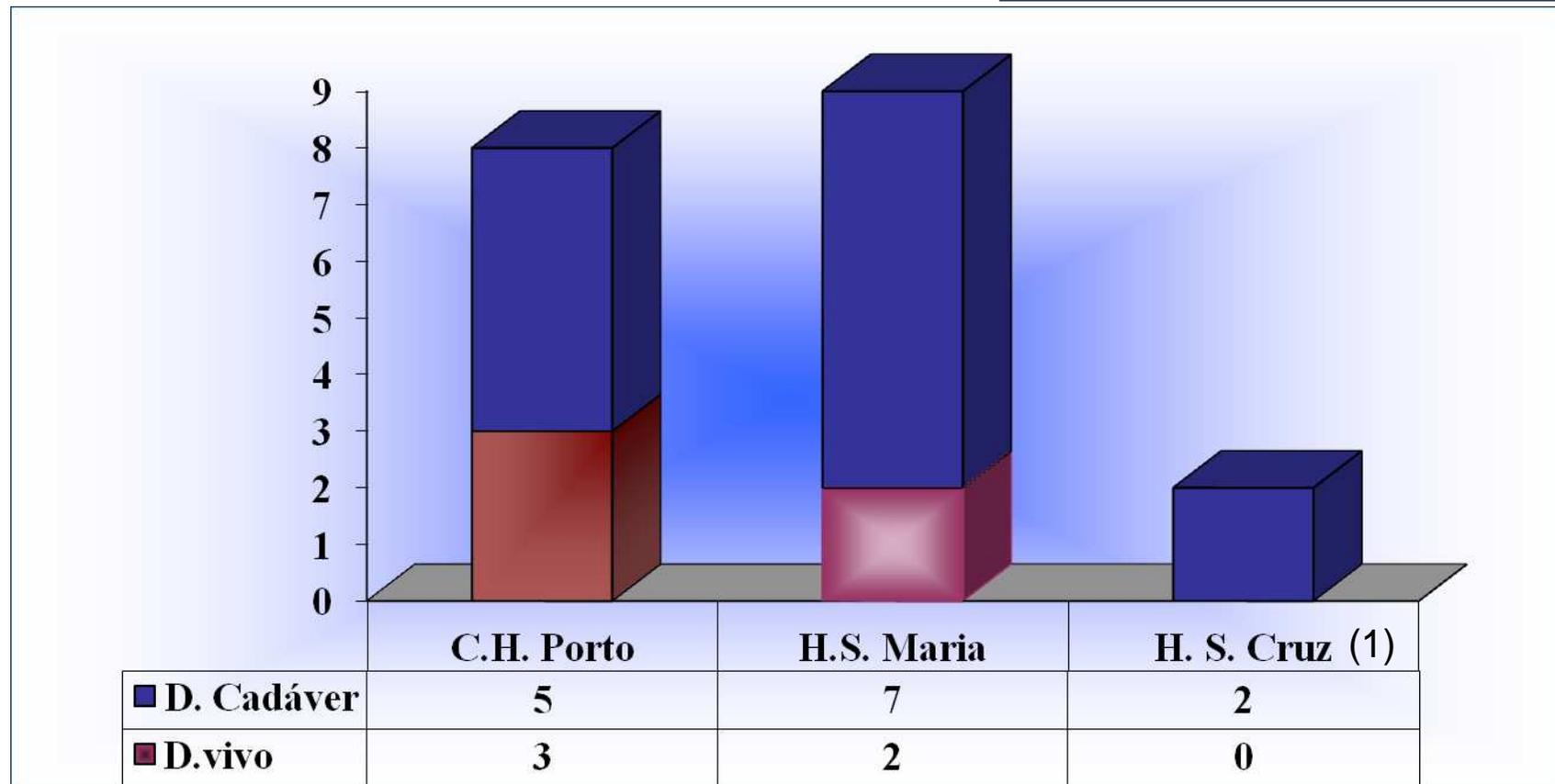
Total =19 doentes

Novos doentes/idade

	<15 anos	>=15 anos
Diálise peritoneal	13	0
Hemodialise	2	3
Transplante <i>Préemptive</i>	0	1

Actividade de transplantação em idade pediátrica -ano de 2007-

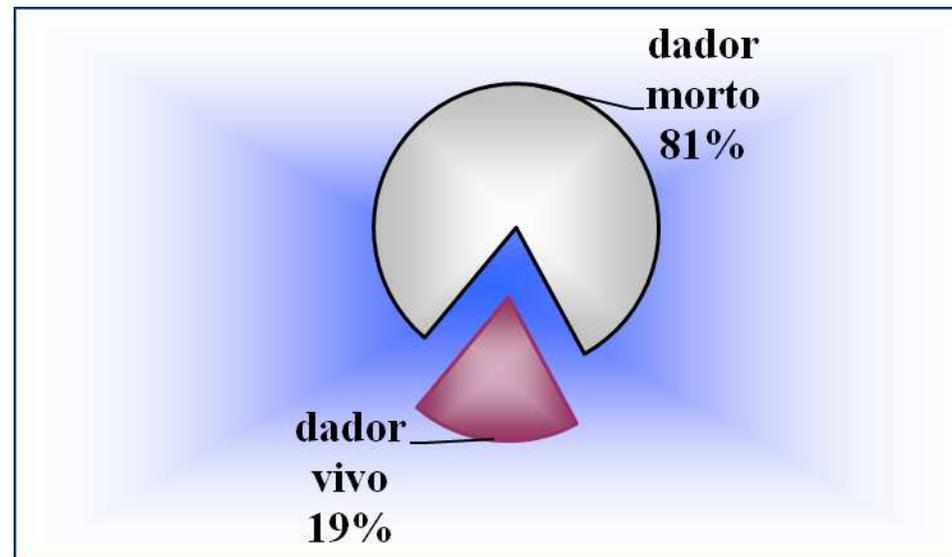
Total = 19 doentes



(1) Provenientes do H. Estefânia

Transplantados renais

- Nº de doentes transplantados seguidos em Unidades pediátricas no ano de 2008: 73
- Transferidos para adultos: 10



- 1 Transplante duplo (fígado e rim)

Prevalência em Dialise Peritoneal

Ano de 2007

- 59 doentes em DP

31/12/2007

- 34 doentes
- Tipo de dialise :
 - DPCA-1 doente
 - DPA (automatizada) -33 doentes

Prevalência em HD

Ano de 2007

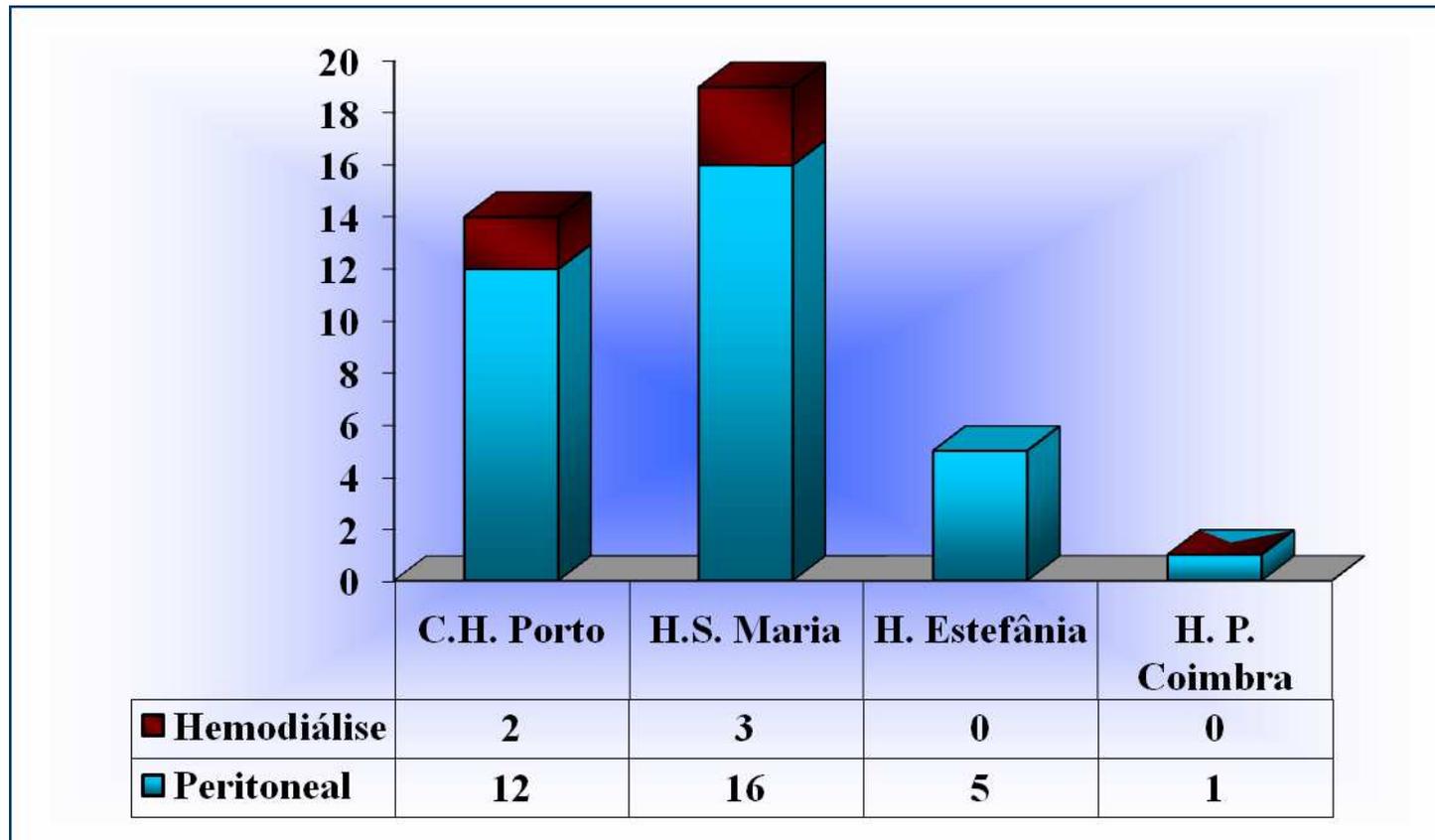
13 doentes em HD

31/12/2007

5 doentes em HD

- Tipo de hemodialise:
 - HD convencional- 4 doentes
 - Hemodiafiltração “on-line”-1 doente
- Acesso vascular: 3 FAV e 2 cateter venoso central

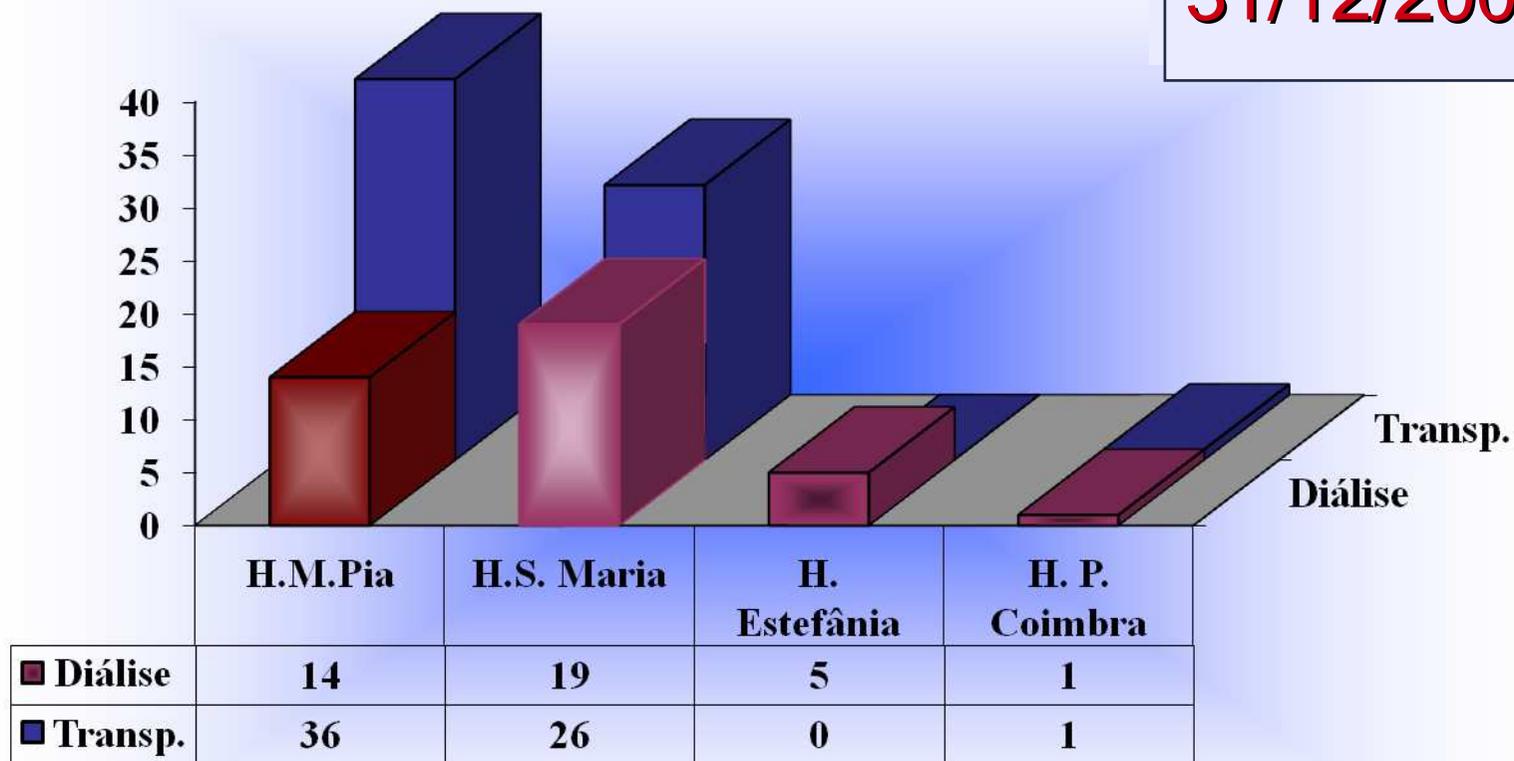
Prevalência em dialise a 31/12/2007



Total = 39
doentes

Prevalência em TSR

31/12/2007



Movimento de doentes -ano de 2007-

Novos doentes	19	Mortos	2
Falência TR	1	Transplantados	19
DP para HD	3	HD para DP	3
Transferidos para adultos	14	Recuperação da FR	1

Evolução do registo

Ano	Novos doentes	Transplante / ano	Nº doentes registados com idade < 20 anos
2005	15	11	80
2006	15	9	111
2007	19	19	104

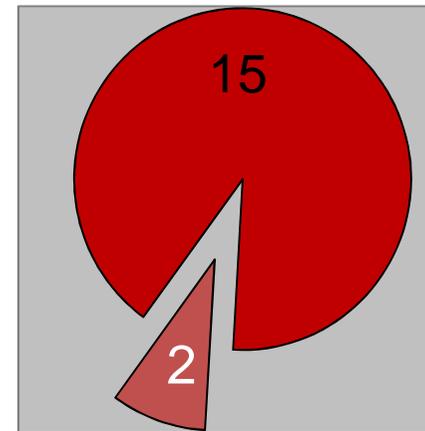
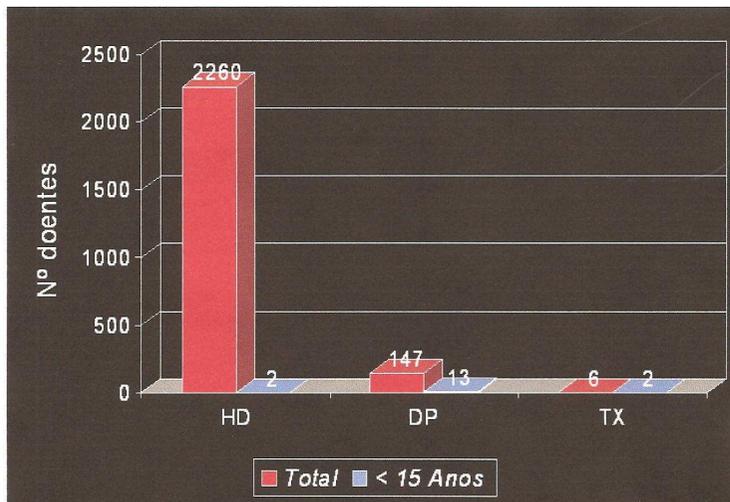
Reflexões

- 1) Divulgação
- 2) Realidade nacional

Reflexões

- Doentes que iniciaram TSR com idade < 15 anos em 2007 em Portugal (Ni=2439)
(Dados do Registo da SPN)

Doentes que iniciaram tratamento substitutivo da função renal em 2007 (Ni = 2439)



Os 2 que não foram enviados fizeram TR “preemptive”.

Em Portugal

Existem:

- 104 Unidades de hemodiálise
- 23 Unidades de diálise peritoneal
- 9 Unidades de transplantação

Problemas

- 1) Divulgação
- 2) Realidade nacional
- 3) Continuar....dados essenciais ou alargados?

ESPN

- Step 1-3 baseline
- Step 3a transplantation event
- Step 4 events
- Step 5a yearly follow-up dialysis
- Step 5b yearly follow-up transplantation
- Used patient identifiers

Events: death, changes of treatment modality, recovery of renal function and transfer out

[data c](#)

Essential information (required)

Patient identifier

example

For a list of patients with baseline characteristics [click here](#) [search existing patient IDs](#)

baseline patient information

- date of birth

17/Jan/88

- sex

M

- date first RRT

10-01-1990

New event

Save record

Date of change treatment

12-10-1996

Event

Change to PD

OR

ERA-EDTA treatment code

[coding - treatment modalities+ events](#)

Cause of Death

[coding - COD \(ERA-EDTA codes\)](#)

Extended A data (high priority data collection)

Cause of graft failure

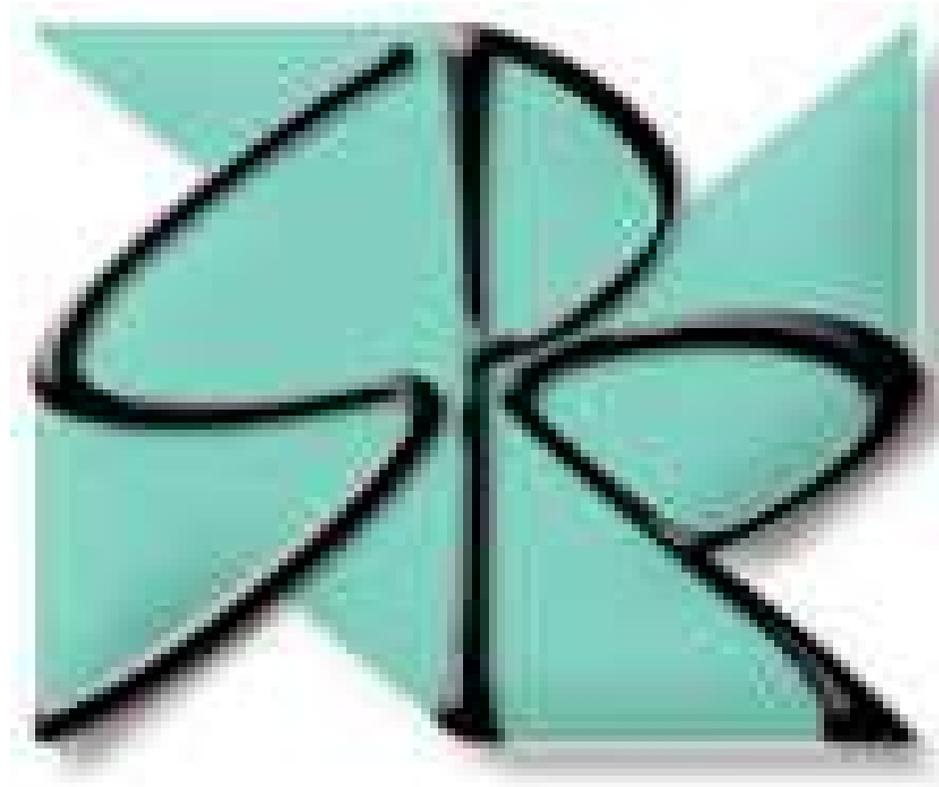
Cause of dialysis failure

Dialysis event /follow-up

Transplantation event

Transplantation follow-up

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