

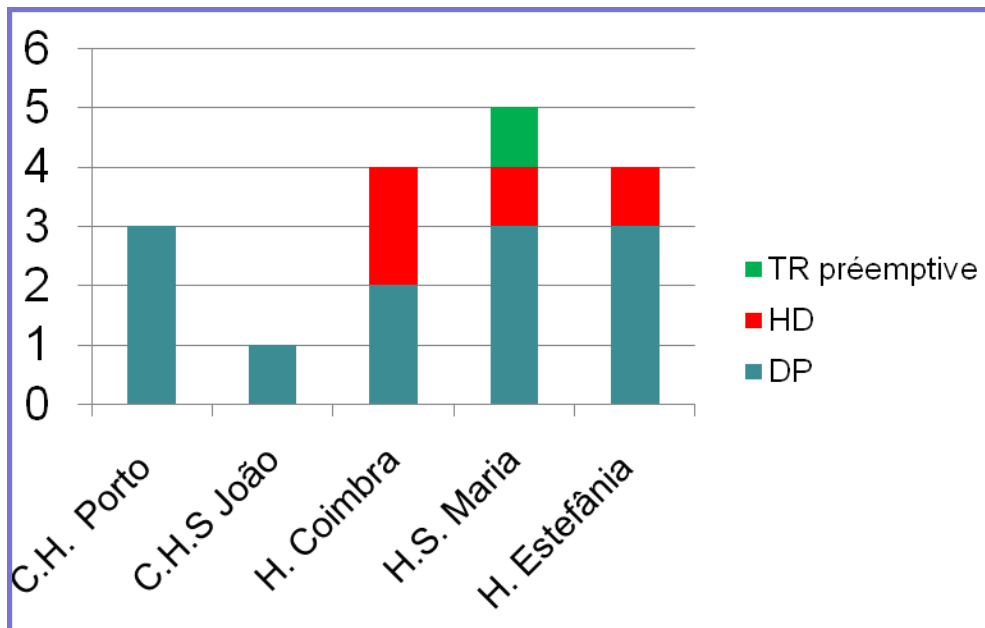


Registo da IRCT 2014

- **Fonte: Registo enviado anualmente para *European Society of Pediatric Nephrology (ESPN)*, com a contribuição das Unidades de Nefrologia Pediátrica Portuguesa.**
- Conceição Mota (C.H.Porto)
- Rosário Stone (H.S. Maria, Lisboa)
- Margarida Abranches (H. D. Estefânia, Lisboa)
- Clara Gomes (H. Pediátrico de Coimbra)
- A Caldas Afonso (C.H.S.João - Porto)

Doentes que iniciaram TSFR no ano de 2014

N=17

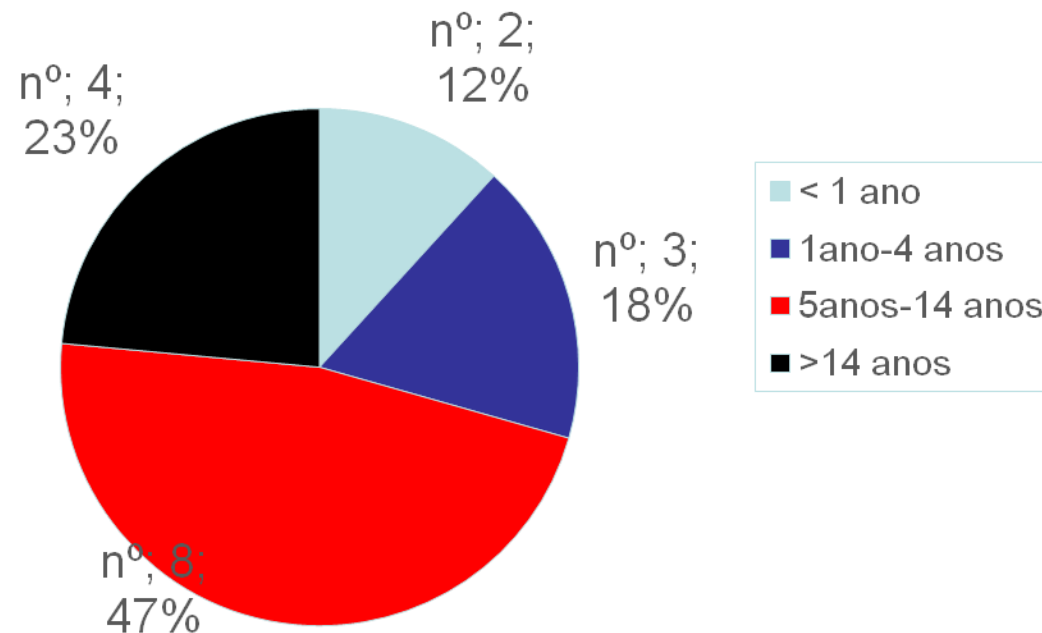


Tipo de TSFR (dia1)
12 em DP
4 em HD
1 Tr pré-emptive.

Idade à data da 1º TSFR

Doentes incidentes em 2014

Média=8,1± 3,5 anos



-ano de 2014-

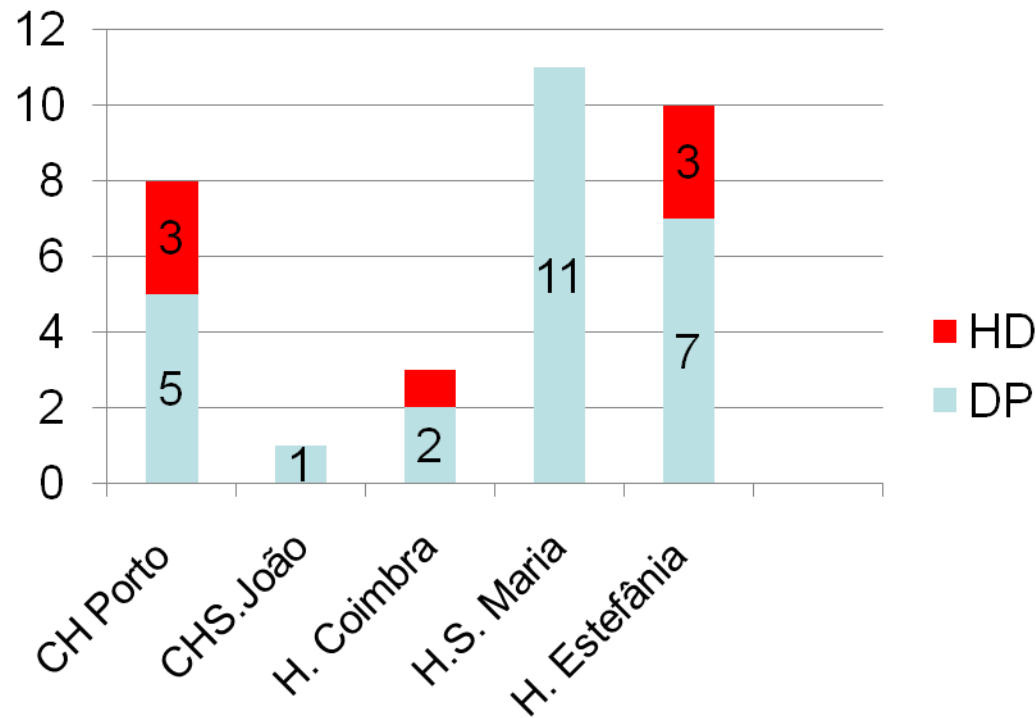
<i>IN</i>	
Novos doentes	17
Perda de TR	0

<i>OUT</i>	
Número de TR	7
Mortos	0
Recuperação da FR	1
Saída de registo → transferência adultos	6



Prevalência pontual de doentes em diálise em ambiente pediátrico (31/12/2014)

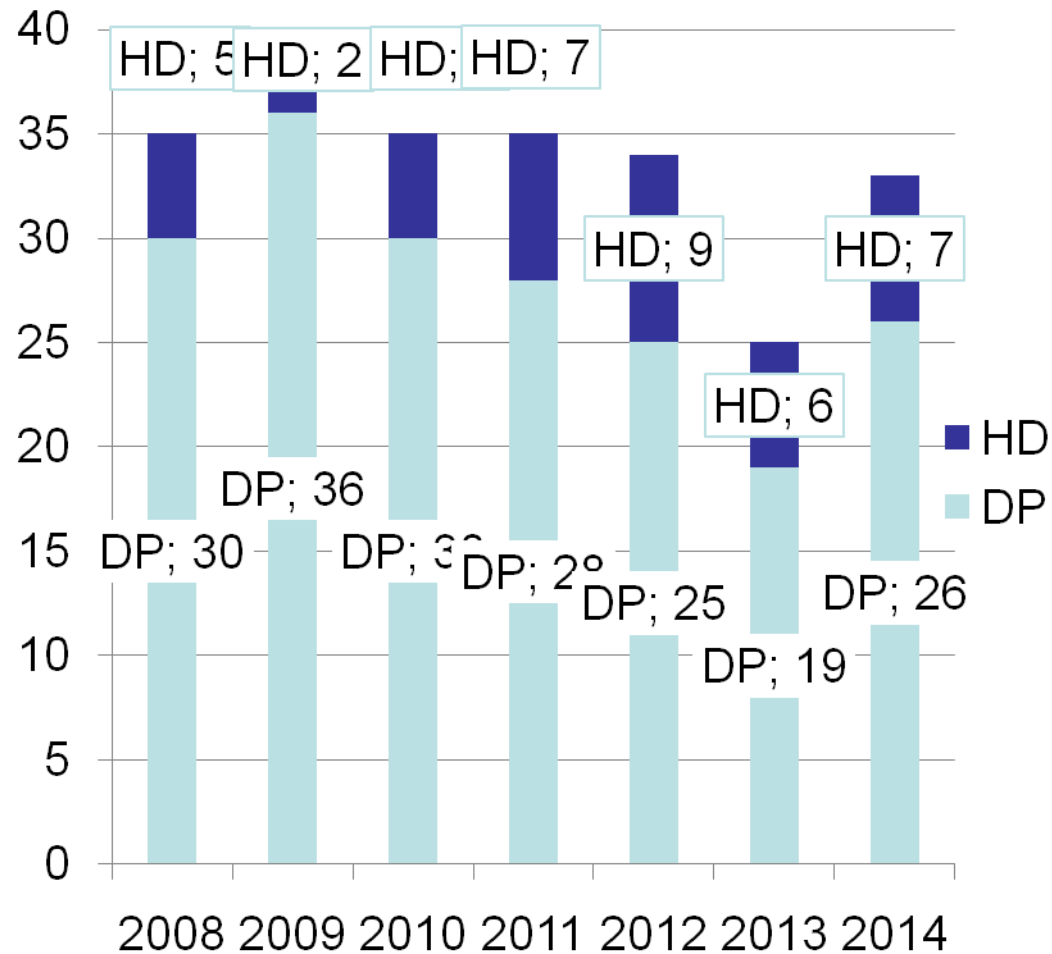
N=33



DP=26(79%)
HD=7(21%)

Evolução do registo

Prevalência pontual de doentes em diálise
a 31 de Dezembro



Transplante

7 transplantes

- 2 Centro Hospitalar do Porto
 - 2 Hospitais Universitários de Coimbra/Pediátrico
 - 2 H. S. Maria. Lisboa
 - 1. H.Curry Cabral .Lisboa
-
- Dador. Rim de cadáver.
 - Transplantados com sucesso

Prevalência pontual de doentes com transplante renal
(enxerto funcionante) com seguimento em
ambiente pediátrico a 31/12/2014

N=80

H S Maria-Lisboa	46
C Hospitalar Porto	29
H Pediátrico Coimbra	5

Etiologia da IRC dos doentes prevalentes com idade <18 anos em TSFR

(31/12/2014)

n=113

Malformações do rim e tracto urinário (CAKUT) códigos EDTA 20,21,22,23,24,25,29 60,61,63,66)	52 (48,5%)
Nefropatias hereditárias incluindo S.N. tipo Finnish (códigos 50,51,52,53,54, 59)	12 (10,4%)
Doenças quísticas hereditárias (códigos 40,41,42,43,49)	7 (5,7%)
Glomerulonefrite e glomerulosclerose (códigos 10,11,12,13,14,15,16,17,19)	19 (17,1%)
Síndrome hemolítico urémico (códigos 88)	7 (6,6%)
Outras (85,90,91,99)	8 (6,1%)
Desconhecida	8 (6,1%)

(1) Estão incluídos os doentes que iniciaram TSFR nas unidades de Nefrologia Pediátrica

Incidência de doentes em TSFR (corrigida)

(per million of the age –related population)

	Incidência (0-18 anos) Nº	Incidência ⁽¹⁾ (0-14 anos) Nº	Incidência ⁽¹⁾ (0-14 anos) pmart
2007	19	16	9,8
2008	16	13	7,9
2009	18	15	9,3
2010	17	11	6,7
2011*	18	15	9,5
2012	24	16	10,2
2013	11	7	4,7
2014	17	13	8,5

Nº de Crianças na população Portuguesa(0-14 anos)- 1. 633. 245 /novos censos* 1.561.550 crianças

Prevalência pontual de crianças com idade inferior a 15 anos em TSFR

Nº de Crianças na população Portuguesa(0-14 anos)- 1. 633. 245 c/ 1.568228 rcianças

Ano	Prevalência ⁽¹⁾ (0-14 anos) Nº	Prevalencia ⁽¹⁾ (0-14 anos) pmart	Prevalencia 15-19 anos N (pmart)
31/12/2007	64	39,2	
31/12/2008	56	34,4	
31/12/2009	70	43,2	
31/12/2010	77	47,1	
31/12/2011*	77	49,1	
31/12/2012	84	53,8	57 (91,7pmart)
31/12/2013	80	52,1	61 (121pmart)
31/12/2014	84	53,8	63 (110pmart)

* Novos censos da população portuguesa



Evolução do registo

Ano	Novos doentes	Transplante / ano
2006	15	9
2007	19	17
2008	16	18
2009	18	16
2010	17	17
2011	18	16
2012	24	17
2013	10	17
2014	17	7

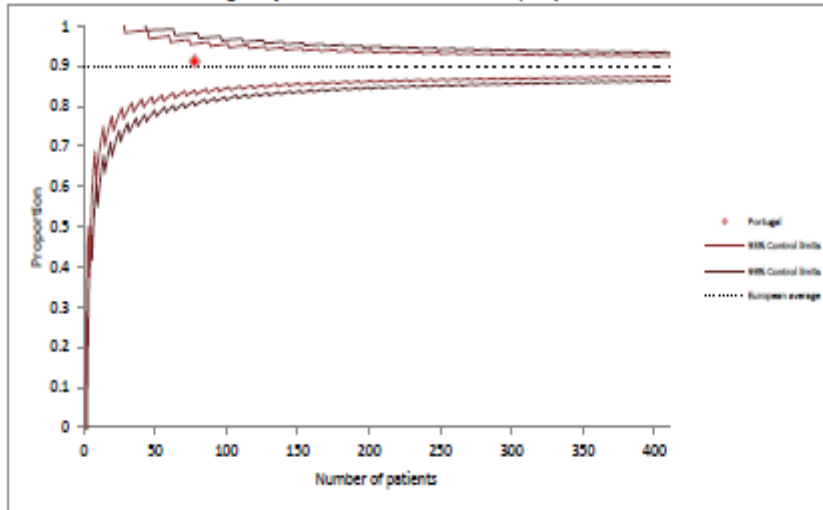
Preliminary Benchmarking Report

Funnel-plots allow us to objectively compare the performance of individual countries. For each clinical indicator, country estimates (y-axis) are plotted against the number of patients (x-axis). The control limits form a 'funnel' around the European average and reflect the precision of the estimate based on the number of patients in each country. Countries that fall outside these limits are doing either better or worse compared to the European average. Nevertheless, in countries with a small number of patients (<10), these limits may be imprecise. The plots are based on patient measurements collected since 2007 for patients aged 0-14 years. All country estimates are adjusted for the effect of age. Details on the methods used can be found in the appendix.

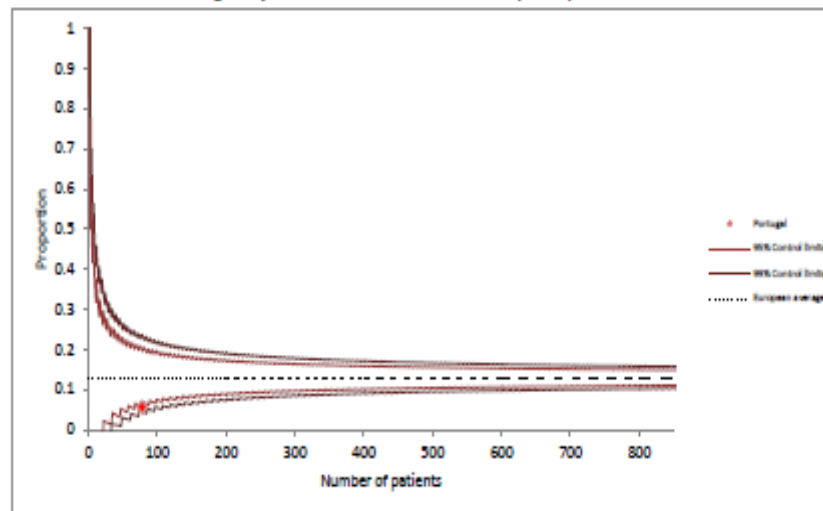
Dados fornecidos em Outubro de 2015 pelo
ESPN registry,
Comparação de Portugal com a média da Europa

Preliminary Benchmarking Report

Age-adjusted ESA treatment in dialysis patients

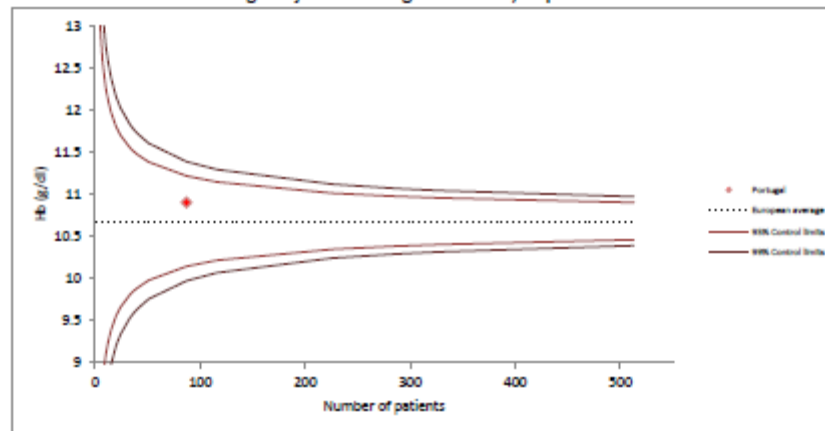


Age-adjusted ESA treatment in transplant patients

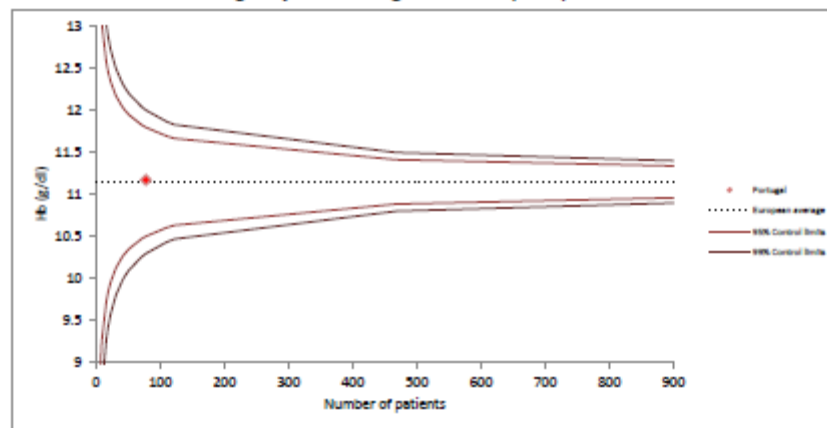


Preliminary Benchmarking Report

Age-adjusted average Hb in dialysis patients



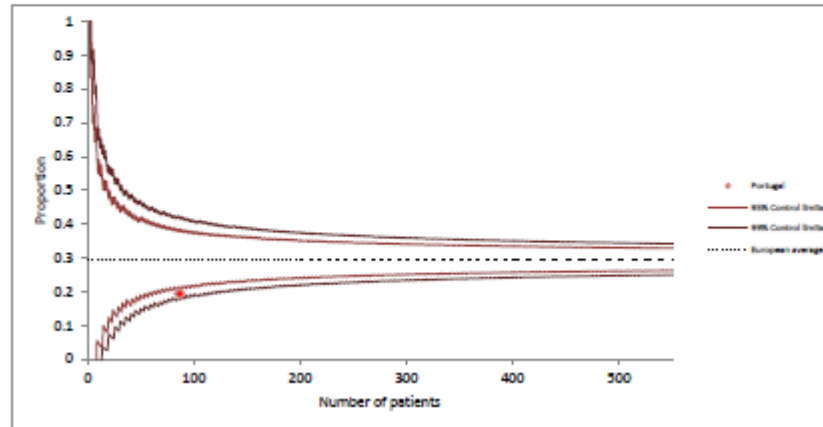
Age-adjusted average Hb in transplant patients



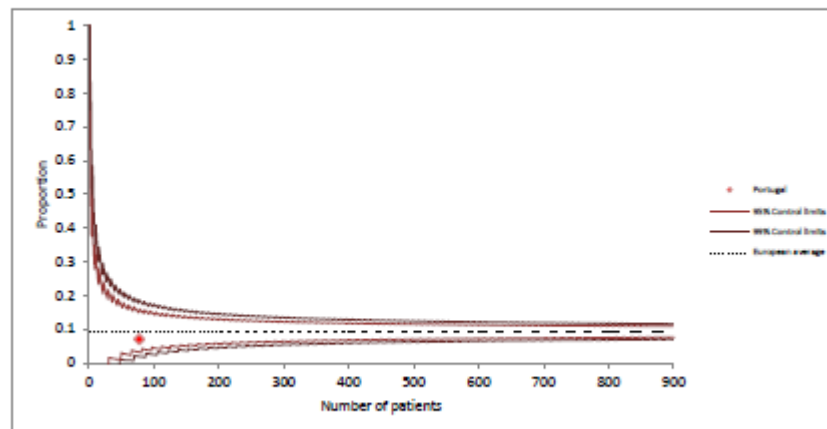
Ponto vermelho Portugal

Preliminary Benchmarking Report

Age-adjusted proportion of anemia (Hb < 10 g/l) in dialysis patients

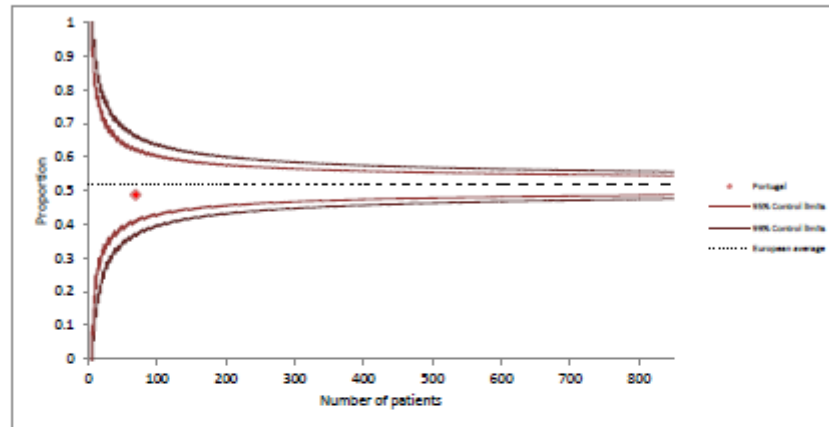


Age-adjusted proportion of anemia (Hb < 10 g/l) in transplant patients

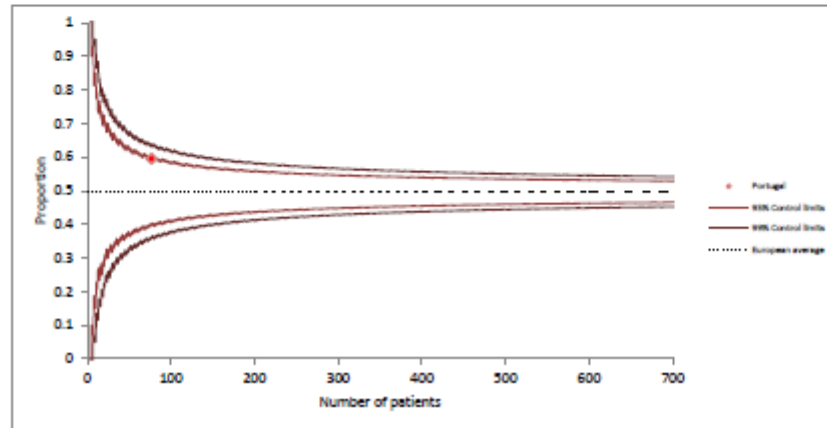


Preliminary Benchmarking Report

Age-adjusted proportion of dialysis patients treated with antihypertensives

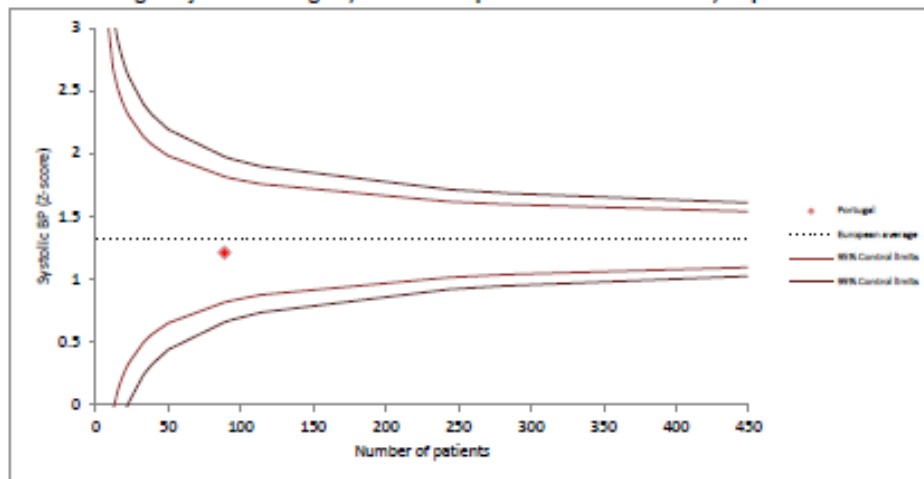


Age-adjusted proportion of transplant patients treated with antihypertensives

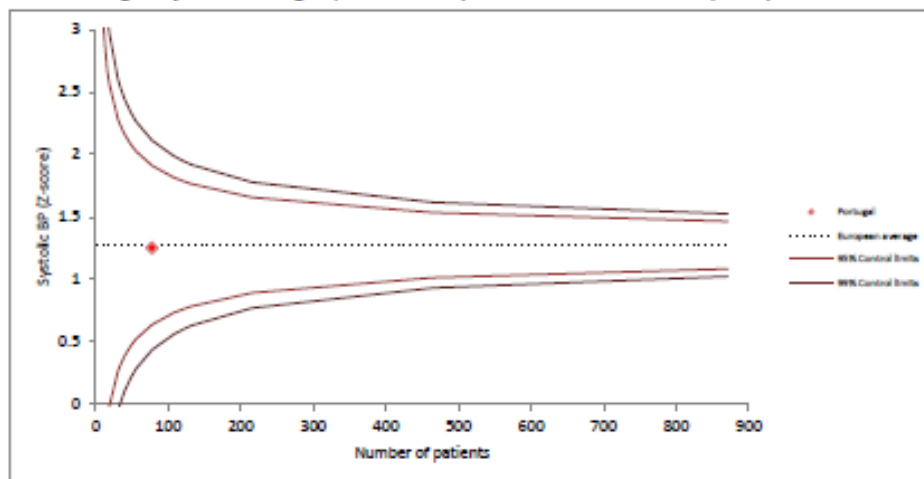


Preliminary Benchmarking Report

Age-adjusted average systolic blood pressure Z-score for dialysis patients

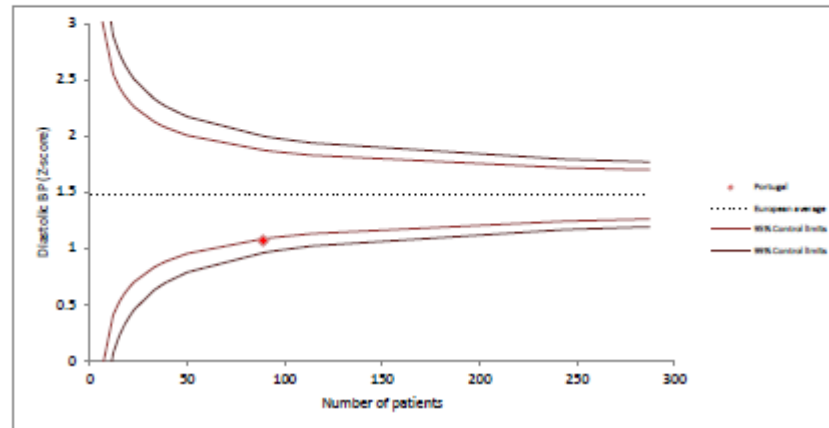


Age-adjusted average systolic blood pressure Z-score for transplant patients

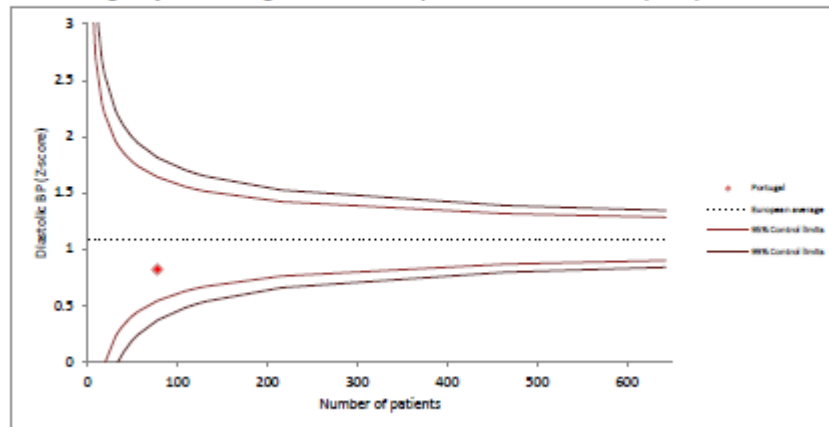


Preliminary Benchmarking Report

Age-adjusted average diastolic blood pressure Z-score for dialysis patients

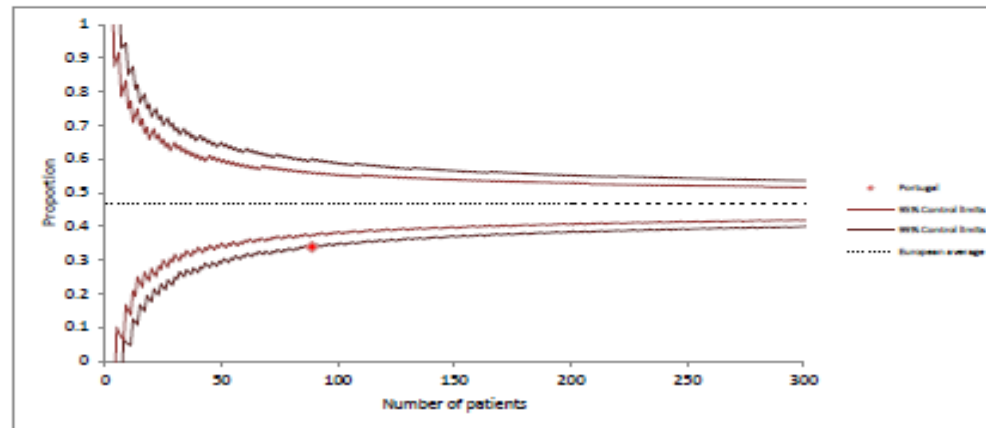


Age-adjusted average diastolic blood pressure Z-score for transplant patients

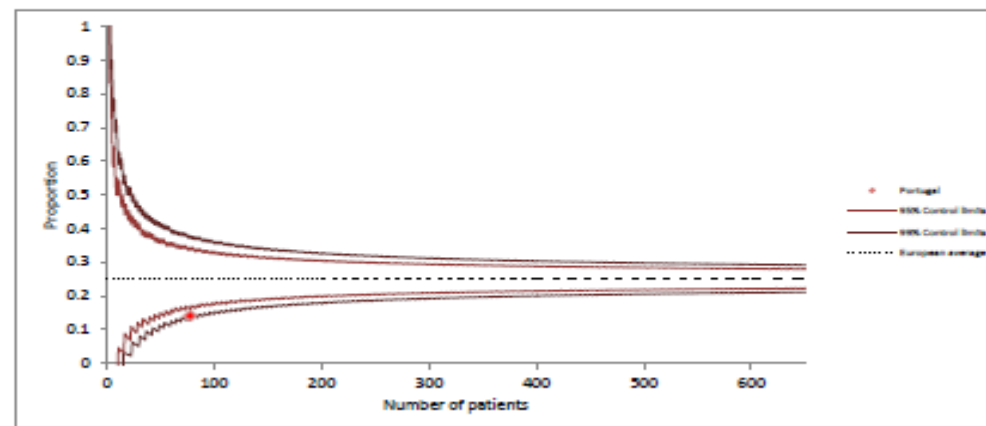


Preliminary Benchmarking Report

Age-adjusted proportion of dialysis patients with hypertension (systolic or diastolic pressure Z-score > 1.64)

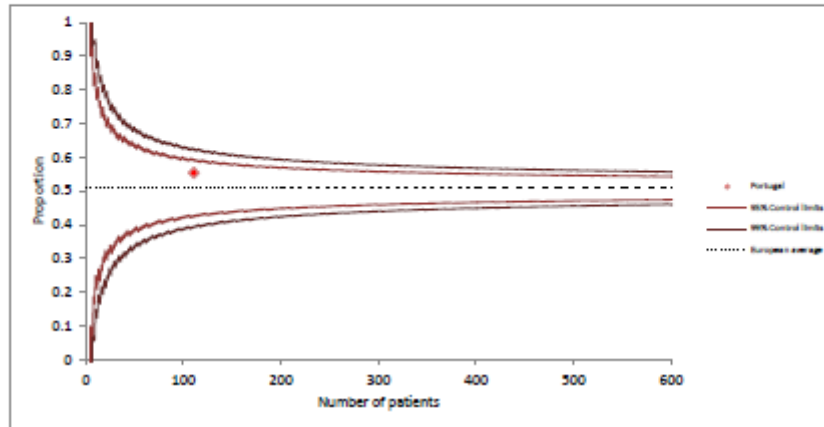


Age-adjusted proportion of transplant patients with hypertension (systolic or diastolic pressure Z-score > 1.64)

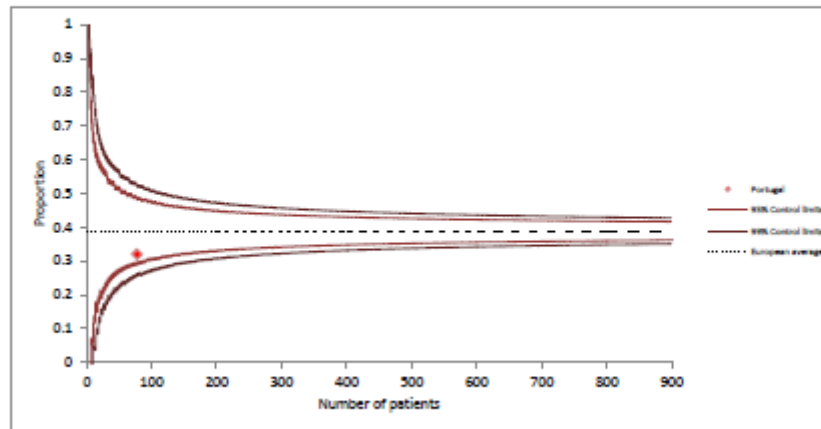


Preliminary Benchmarking Report

Age-adjusted proportion of dialysis patients with a height Z-score below -2

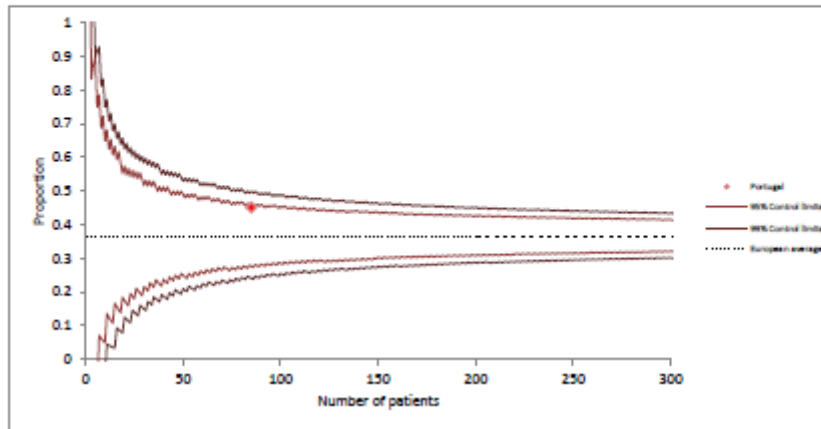


Age-adjusted proportion of transplant patients with a height Z-score below -2

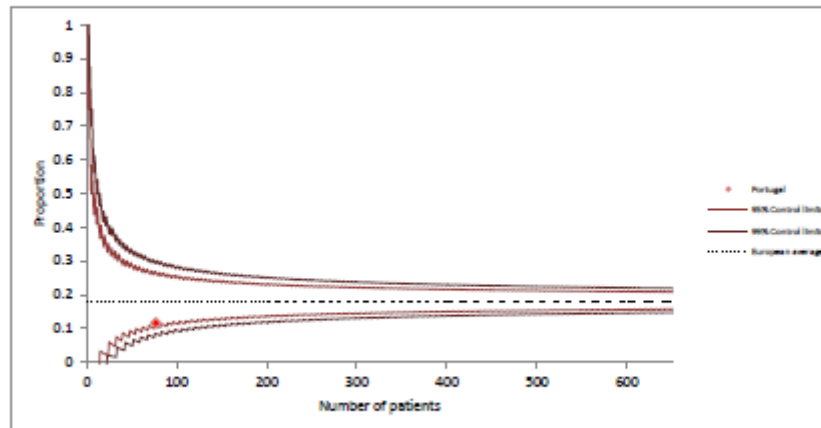


Preliminary Benchmarking Report

Age-adjusted proportion of dialysis patients with hypercholesterolemia (>200 mg/dl)

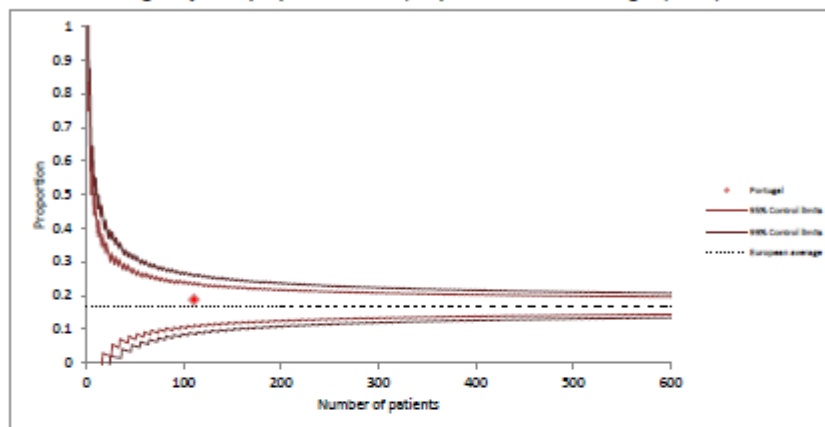


Age-adjusted proportion of transplant patients with hypercholesterolemia (>200 mg/dl)

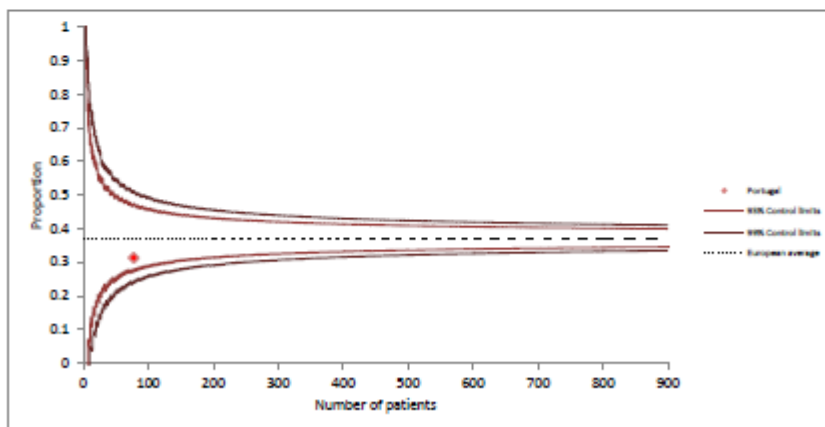


Preliminary Benchmarking Report

Age-adjusted proportion of dialysis patients with overweight (BMI*)



Age-adjusted proportion of transplant patients with overweight (BMI*)



* For children <2 years, overweight was defined as Z-score > 2 based on WHO growth standards. For older patients, BMI was expressed according to height-age and categorized according to cut-offs defined by the International Obesity Taskforce

Publicações da ESPN/ERA-EDTA (participação de nefrologistas portugueses 2010-14)

- [Determinants of eGFR at start of renal replacement therapy in paediatric patients.](#) Tizard EJ, Jager KJ, Schaefer F, Vondrak K, Groothoff JW, Podracká L, Holmberg C, Jankauskiené A, Lewis MA, van Damme-Lombaerts R, **Mota C**, Niaudet P, Novljan G, Peco-Antic A, Sahpazova E, Toots U, Verrina E. *Nephrol Dial Transplant*. 2010 Oct;25(10):3325-32.
- [Underweight, overweight and obesity in paediatric dialysis and renal transplant patients.](#) Bonthuis M, van Stralen KJ, Verrina E, Groothoff JW, Alonso Melgar A, Edefonti A, Fischbach M, **Mendes P**, Molchanova EA, Paripović D, Peco-Antic A, Printza N, Rees L, Rubik J, Stefanidis CJ, Sinha MD, Zagazdzon I, Jager KJ, Schaefer F; *NDT* 2013; 0:1-10
- [Demographics of paediatric renal replacement therapy in Europe: a report of the ESPN/ERA-EDTA registry.](#) Chesnaye N, Bonthuis M, Schaefer F, Groothoff JW, Verrina E, Heaf JG, Jankauskiene A, Lukosiene V, Molchanova EA, **Mota C**, Peco-Antić A, Ratsch IM, Bjerre A, Roussinov DL, Sukalo A, Topaloglu R, Van Hoeck K, Zagazdzon I, Jager KJ, Van Stralen KJ; on behalf of the ESPN/ERA-EDTA registry. *Pediatr Nephrol*. 2014 Jul 21.
- [Adult height in patients with advanced CKD requiring renal replacement therapy during childhood.](#) Harambat J, Bonthuis M, van Stralen KJ, Ariceta G, Battelino N, Bjerre A, Jahnukainen T, Leroy V, Reusz G, **Sandes AR**, Sinha MD, Groothoff JW, Combe C, Jager KJ, Verrina E, Schaefer F; ESPN/ERA-EDTA Registry. *Clin J Am Soc Nephrol*. 2014 Jan;9(1):92-9.

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• [Bonthuis M¹](#), [Busutti M¹](#), [van Stralen KJ²](#), [Jager KJ¹](#), [Baiko S¹](#), [Bakkaloğlu S¹](#), [Battelino N¹](#), [Gaydarova M¹](#), [Gianoglio B¹](#), [Parvex P¹](#), [Gomes C¹](#), [Heaf JG¹](#), [Podracka L¹](#), [Kuzmanovska D¹](#), [Molchanova MS¹](#), [Pankratenko TE¹](#), [Papachristou F¹](#), [Reusz G¹](#), [Sanahuja MJ¹](#), [Shroff R¹](#), [Groothoff JW¹](#), [Schaefer F¹](#), [Verrina E](#)

Mineral metabolism in European children living with a renal transplant: a European society for paediatric nephrology/european renal association-European dialysis and transplant association registry study. [Clin J Am Soc Nephrol](#). 2015 May 7;10(5):767-75. doi: 10.2215/CJN.06200614. Epub 2015 Feb 20.

• [van Huis M¹](#), [Bonthuis M²](#), [Sahpazova E³](#), [Mencarelli F⁴](#), [Spasojević B⁵](#), [Reusz G⁶](#), [Caldas-Afonso A⁷](#), [Bjerre A⁸](#), [Baiko S⁹](#), [Vondrak K¹⁰](#), [Molchanova EA¹¹](#), [Kolvek G¹²](#), [Zaikova N¹³](#), [Böhm M¹⁴](#), [Ariceta G¹⁵](#), [Jager KJ²](#), [Schaefer F¹⁶](#), [van Stralen KJ²](#), [Groothoff JW¹](#).

Considerable variations in growth hormone policy and prescription in paediatric end-stage renal disease across European countries-a report from the ESPN/ERA-EDTA registry. [Nephrol Dial Transplant](#). 2015 Apr 28. pii: gfv105. [Epub ahead of print]