

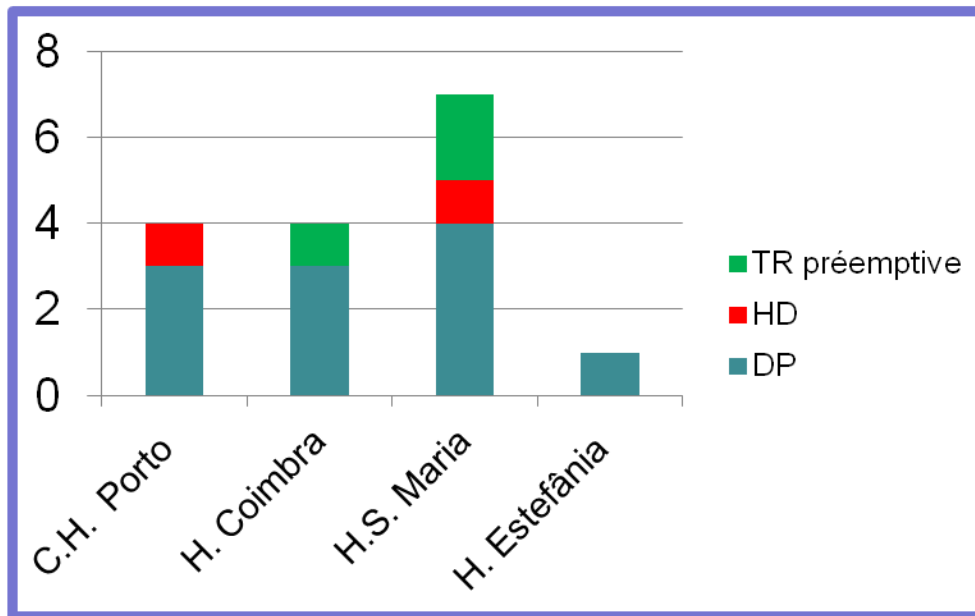
Registo da DRC5 em TSFR 2015



- **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)

Doentes que iniciaram TSFR no ano de 2015

N=16

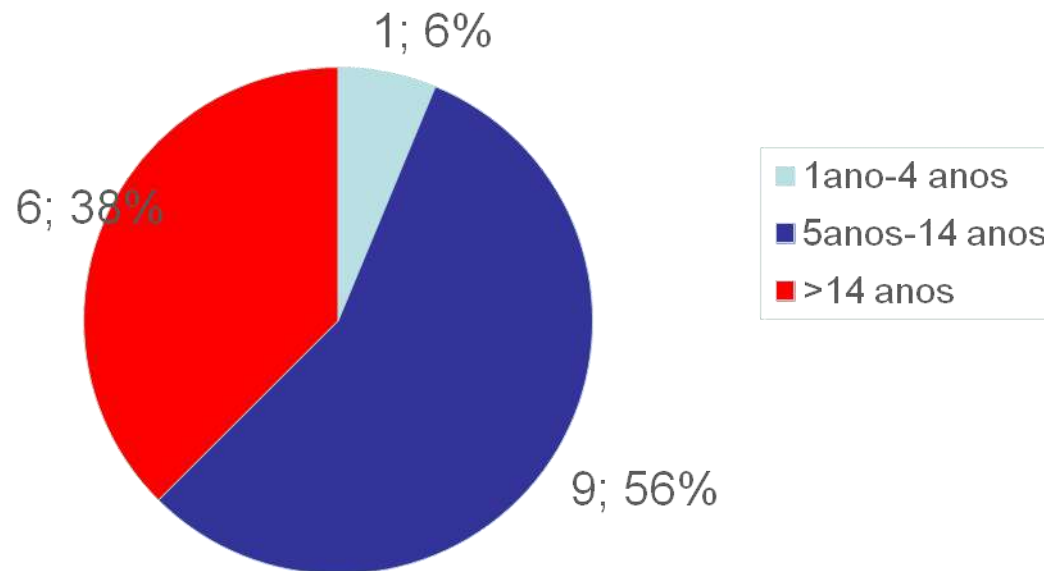


Tipo de TSFR (dia1)
11 em DP
2 em HD
3 Tr préemptive.

Idade à data da 1º TSFR

Doentes incidentes em 2015

Média=11,7± 4,3 anos



-ano de 2015-

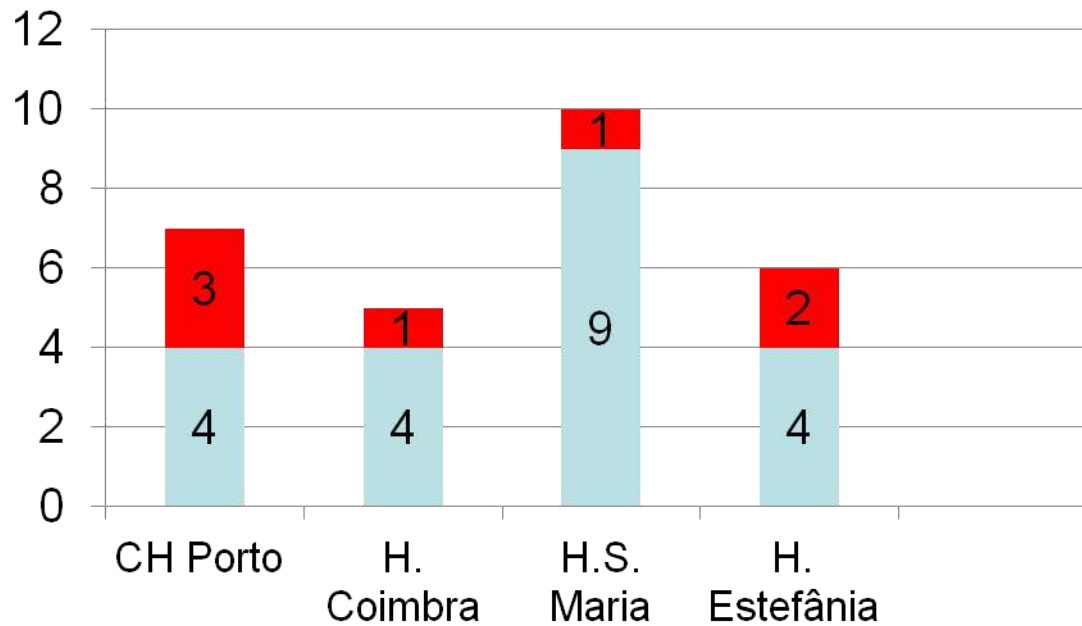
<i>IN</i>	
Novos doentes	16
Perda de TR	0

<i>OUT</i>	
Número de TR	20
Mortos	1
Recuperação da FR	1
Saída de registo → transferência adultos	10



Prevalência pontual de doentes em diálise em ambiente pediátrico (31/12/2015)

N=28

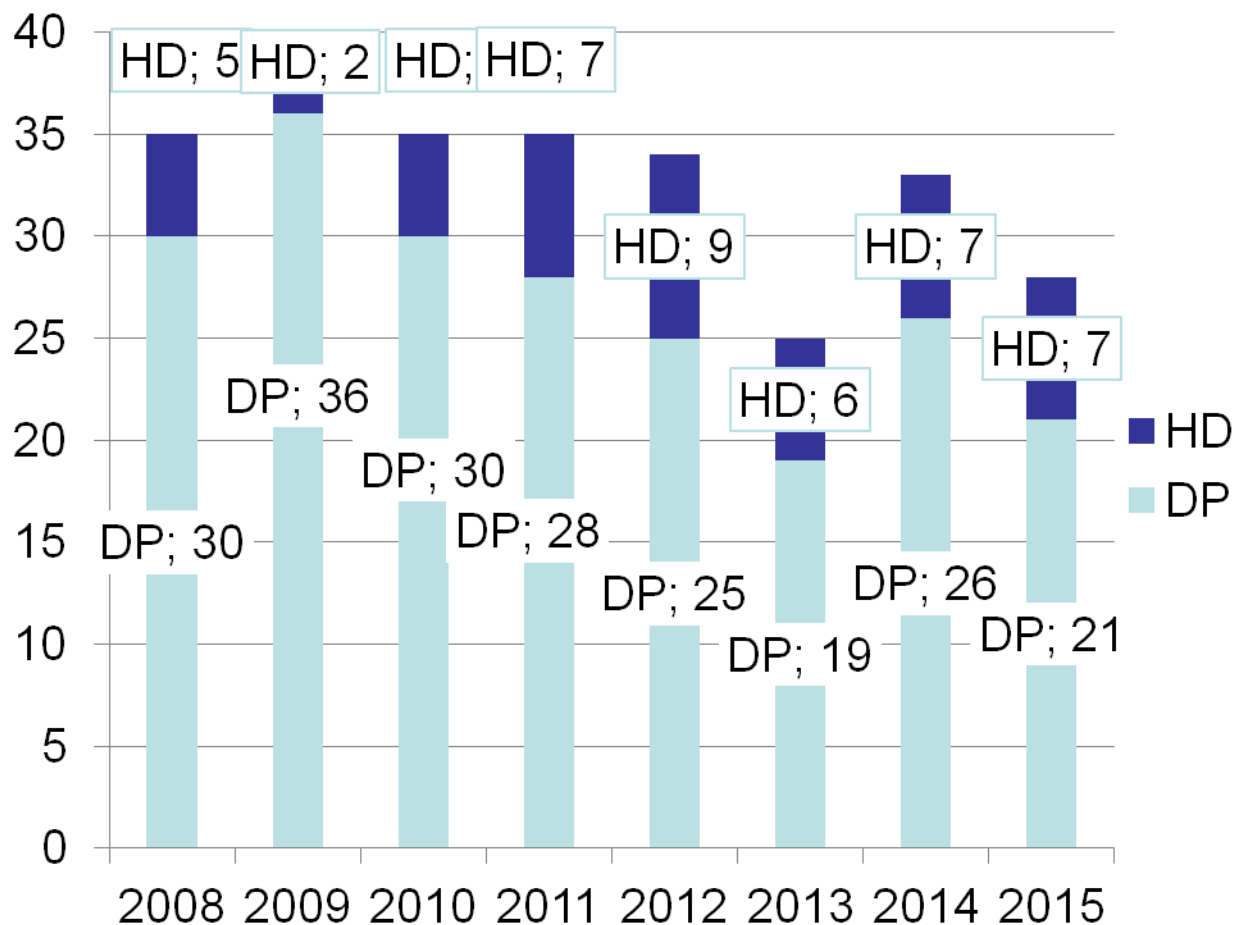


DP=21(75%)
HD=7(25%)

■ HD
■ DP

Evolução do registo

Prevalência pontual de doentes em diálise
a 31 de Dezembro



Transplante

20 transplantes

- Centro Hospitalar do Porto; n=4
 - Hospitais Universitários de Coimbra/Pediátrico; n=3
 - H. S. Maria. Lisboa; n=13
-
- Dador. Rim de dador cadáver; n=15
 - Dador Rim de dador vivo; n= 5
 - Transplantados com sucesso; n=20

Prevalência pontual de doentes com transplante renal
(enxerto funcionante) com seguimento em
ambiente pediátrico a 31/12/2015

N=90

H S Maria-Lisboa	50
C Hospitalar Porto	32
H Pediátrico Coimbra	8

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

(31/12/2015)

Malformações do rim e tracto urinário (CAKUT) códigos EDTA 20,21,22,23,24,25,29 60,61,63,66)	53 (48,5%)
Nefropatias hereditárias incluindo S.N. tipo Finnish (códigos 50,51,52,53,54, 59)	13 (10,4%)
Doenças quísticas hereditárias (códigos 40,41,42,43,49)	8 (5,7%)
Glomerulonefrite e glomerulosclerose (códigos 10,11,12,13,14,15,16,17,19)	20 (17,1%)
Síndrome hemolítico urémico (códigos 88)	8 (6,6%)
Outras (85,90,91,99)	9 (6,1%)
Desconhecida	9 (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
2015	16	10	6,4

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 rcrianças

Ano	Prevalência ⁽¹⁾ (0-14 anos) Nº	Prevalencia ⁽¹⁾ (0-14 anos) p mart	Prevalencia 0-19 anos (p mart)
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	91,7 p mart
31/12/2013	80	52,1	121 p mart
31/12/2014	84	53,8	110 p mart
31/12/2015	85	55,4	112p mart



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
2015	16	20

Preliminary Benchmarking Report

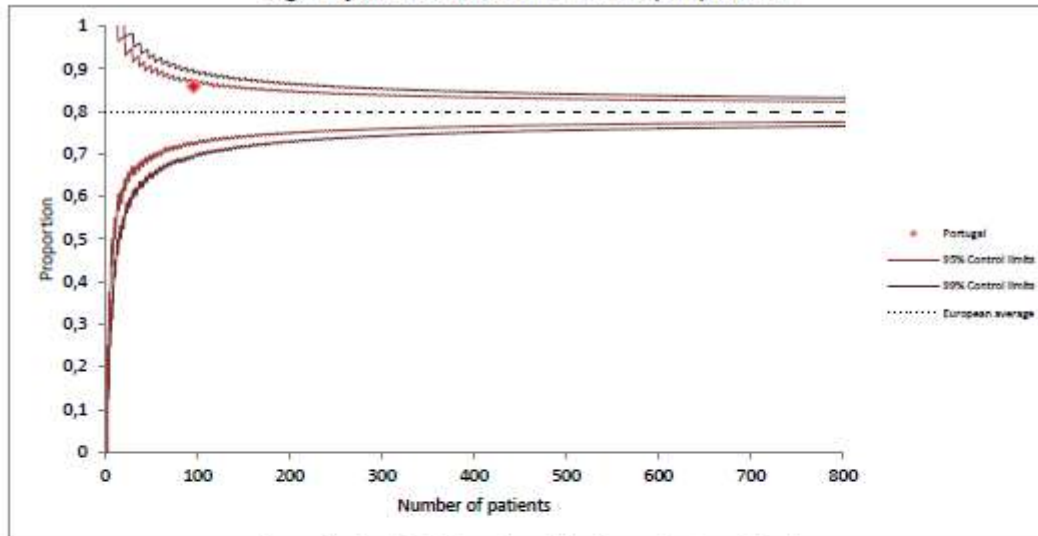
Funnel-plots allow us to objectively compare the performance of individual countries. For each clinical indicator, country estimates (y-axis) are plotted against the number of patients (x-axis). The control limits form a 'funnel' around the European average and reflect the precision of the estimate based 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 Dezembro de 2016 pelo
ESPN registry,
Comparação de Portugal com a média da Europa

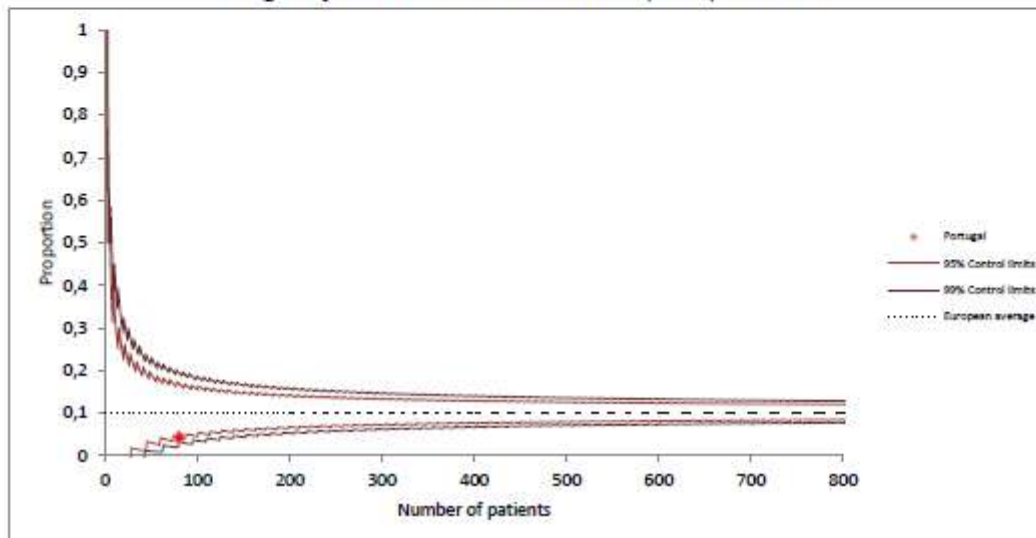
Benchmarking Report

Age-adjusted ESA treatment

Age-adjusted ESA treatment in dialysis patients



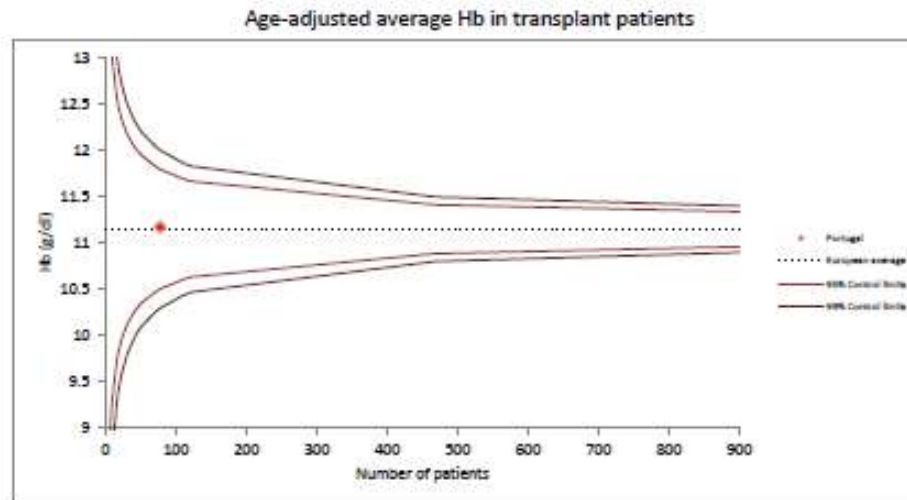
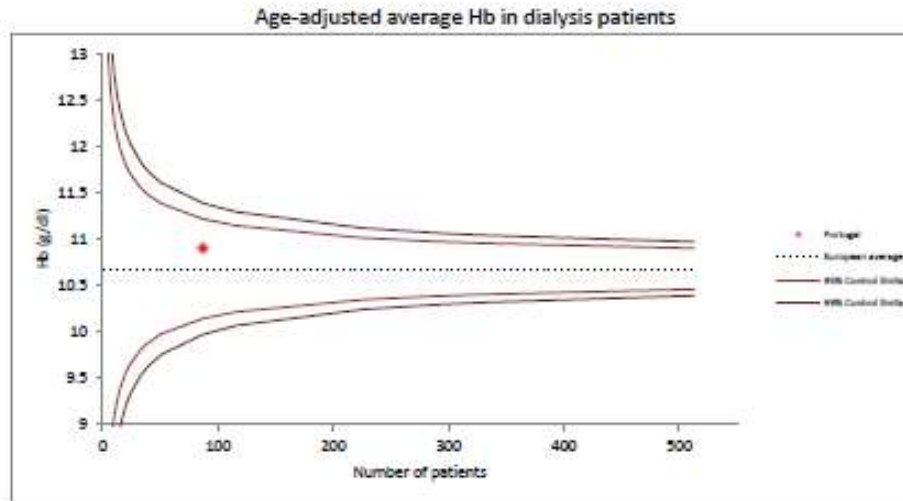
Age-adjusted ESA treatment in transplant patients



Ponto vermelho Portugal

Benchmarking Report

Age-adjusted average Hb

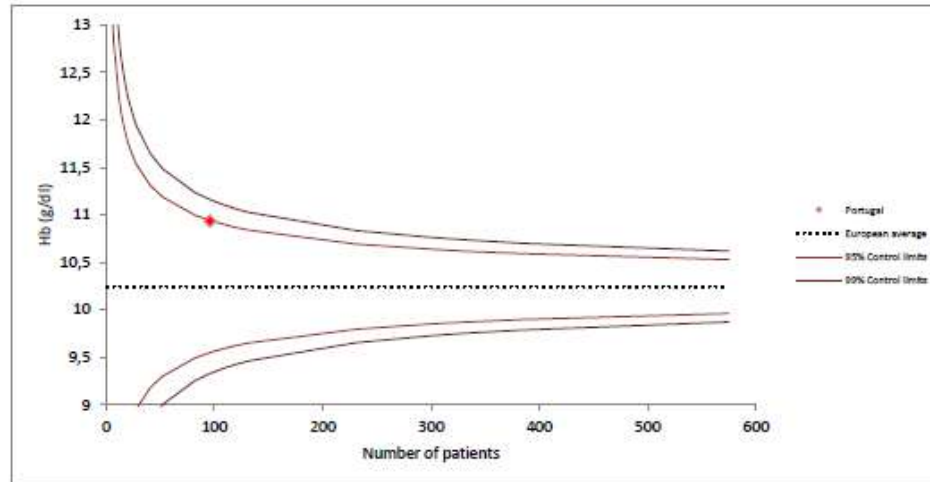


Ponto vermelho Portugal

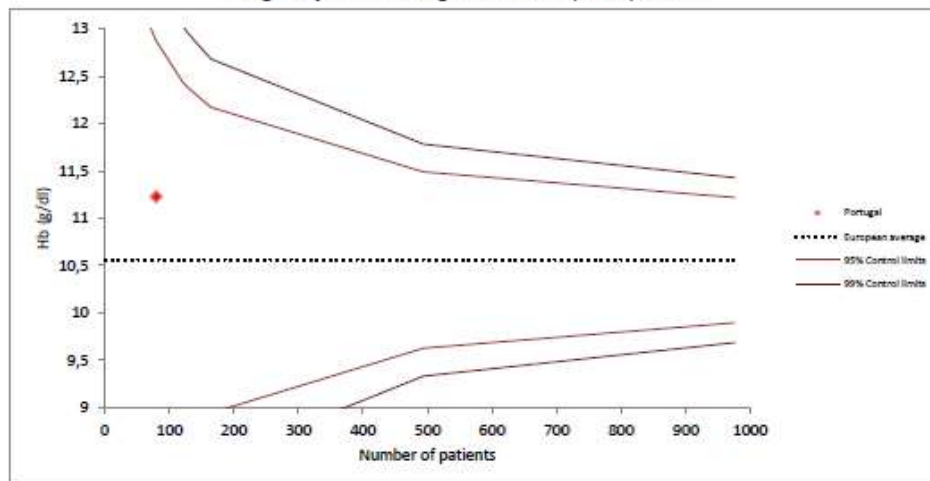
Benchmarking Report

Age-adjusted average Hb

Age-adjusted average Hb in dialysis patients



Age-adjusted average Hb in transplant patients

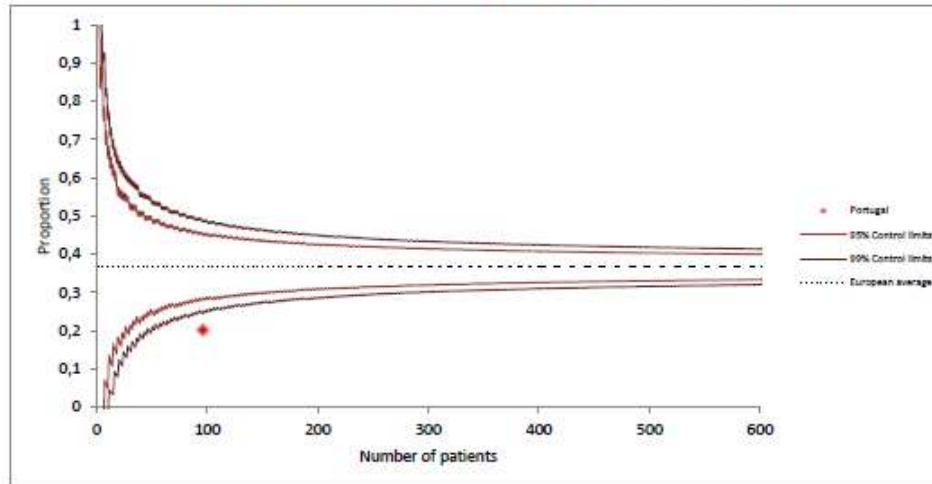


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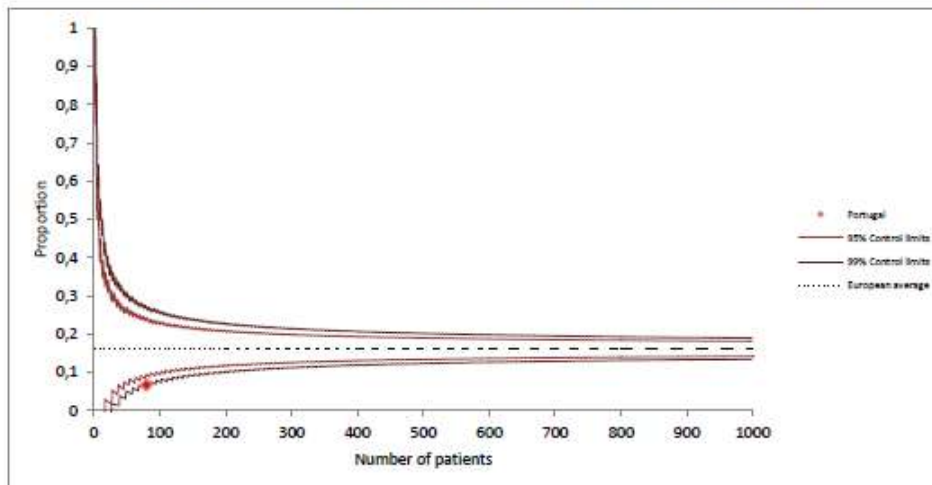
Benchmarking Report

Age-adjusted proportion of anemia

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



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

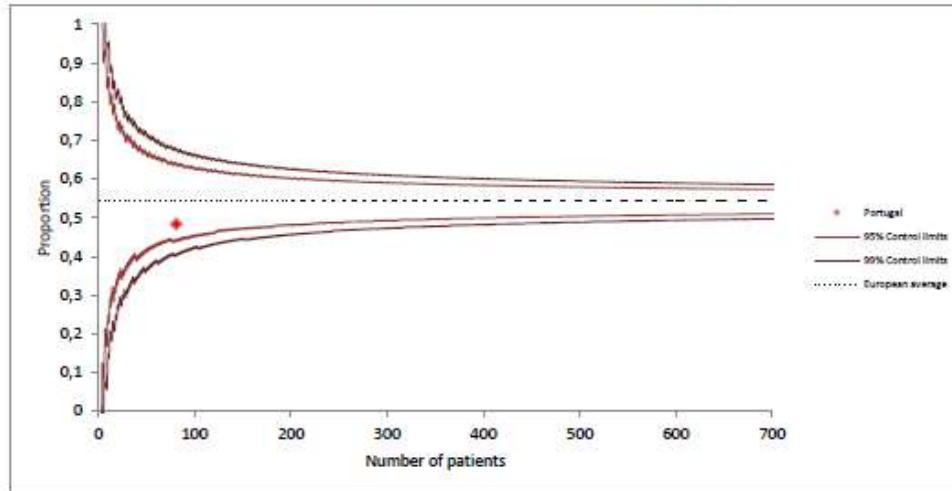


Ponto vermelho Portugal

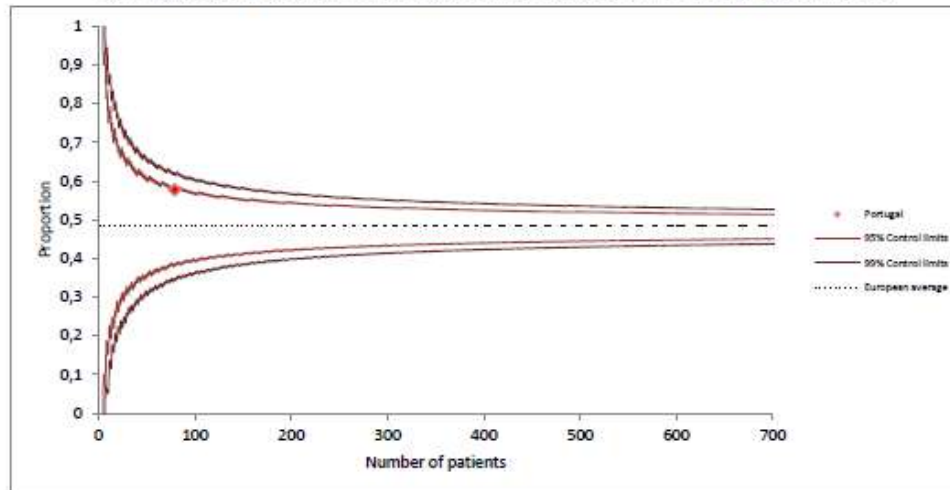
Benchmarking Report

Age-adjusted patients treated with antihypertensives

Age-adjusted proportion of dialysis patients treated with antihypertensives



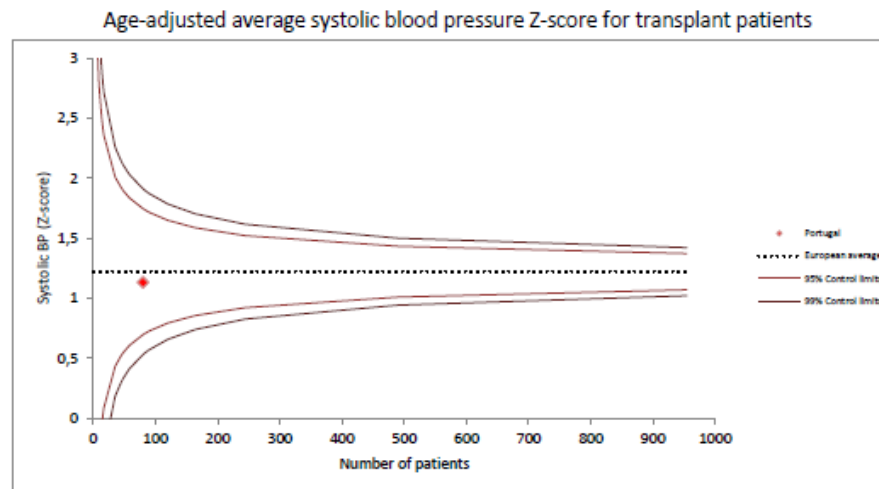
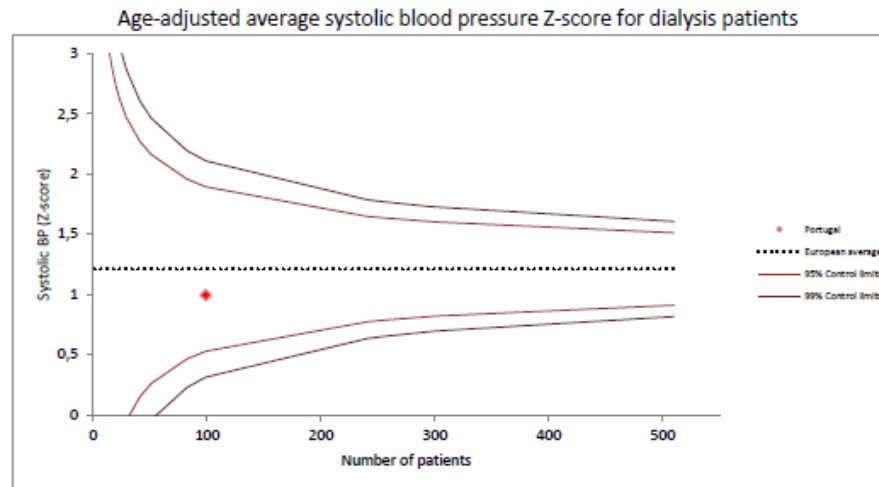
Age-adjusted proportion of transplant patients treated with antihypertensives



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Benchmarking Report

Age-adjusted average systolic blood pressure Z-score



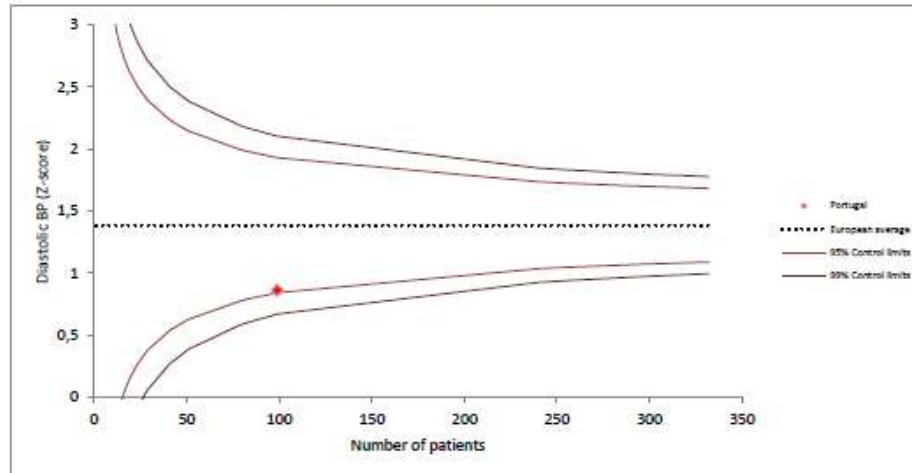
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Blood pressure SDS was calculated following the fourth report of the National High Blood Pressure Education Program (NHBPEP) (National High Blood Pressure Education Program Working Group on High Blood Pressure in Children and Adolescents. The fourth report on the diagnosis, evaluation, and treatment of high blood pressure in children and adolescents. Pediatrics 2004; 114: 555-576)

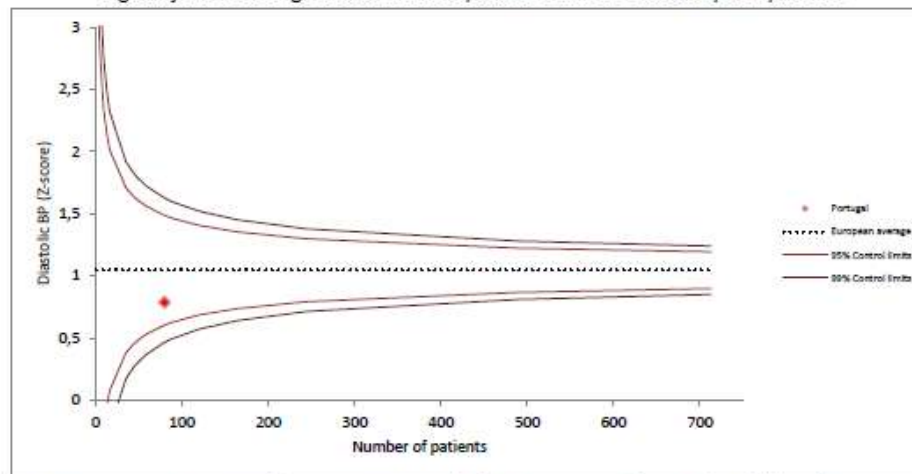
Benchmarking Report

Age-adjusted average diastolic blood pressure Z-score

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



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



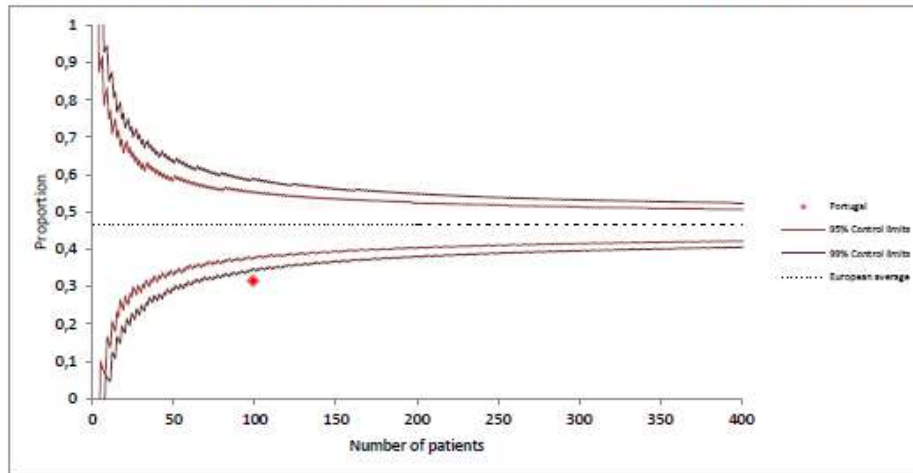
Blood pressure SDS was calculated following the fourth report of the National High Blood Pressure Education Program (NHBPEP) (National High Blood Pressure Education Program Working Group on High Blood Pressure in Children and Adolescents. The fourth report on the diagnosis, evaluation, and treatment of high blood pressure in children and adolescents. *Pediatrics* 2004; 114: 555-576)

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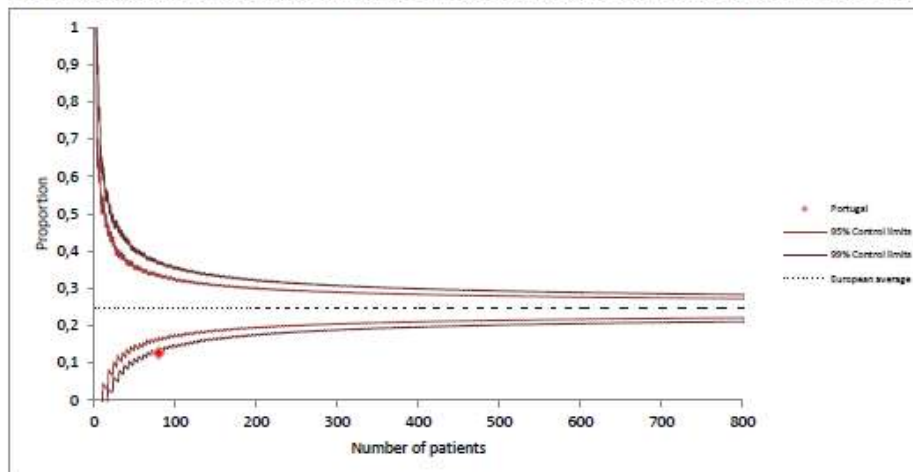
Benchmarking Report

Age-adjusted average systolic or diastolic blood pressure Z-score

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)

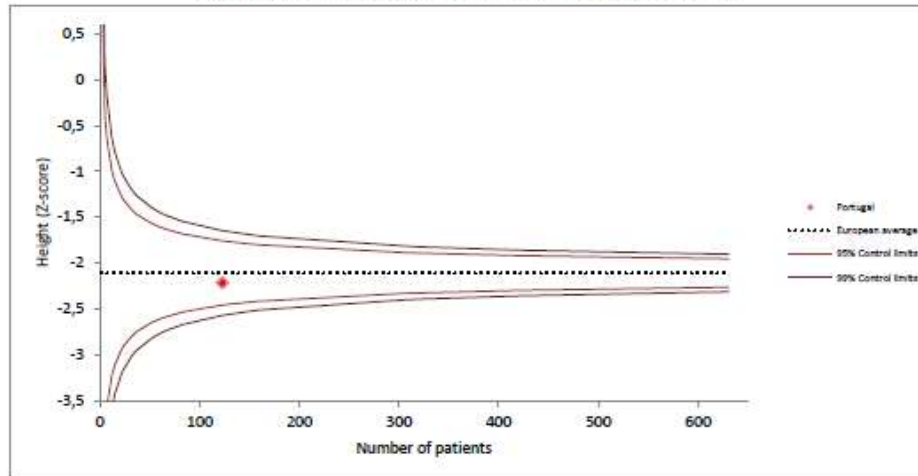


Ponto vermelho Portugal

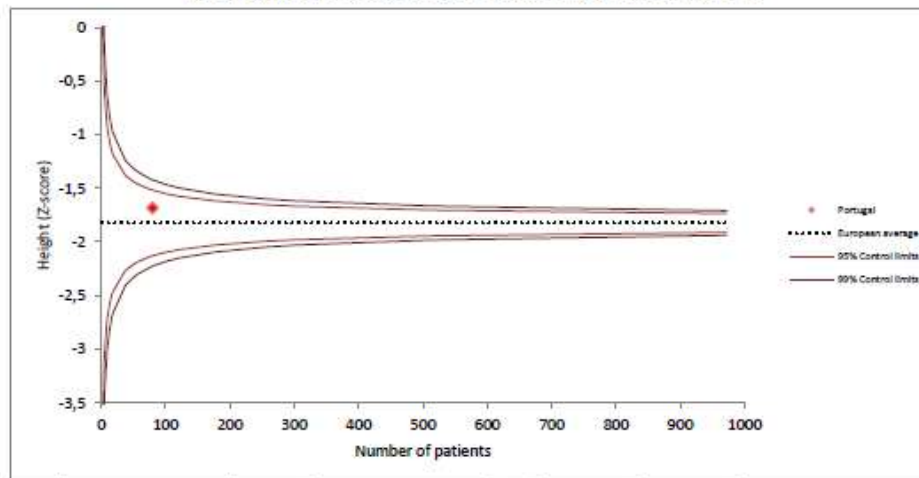
Benchmarking Report

Age-adjusted average height Z-score

Age-adjusted average height Z-score for dialysis patients



Age-adjusted average height Z-score for transplant patients



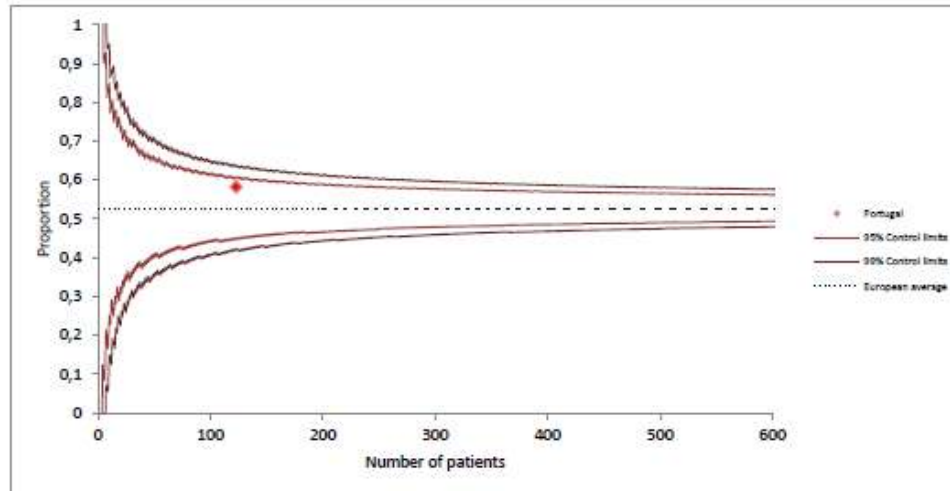
Height SDS was calculated according recent national or European growth charts [Borhuis et al. Use of National and International growth charts for studying height in European children: development of up-to-date European height-for-age charts. PLoS ONE 2012; 7(8): e42506]

Ponto vermelho Portugal

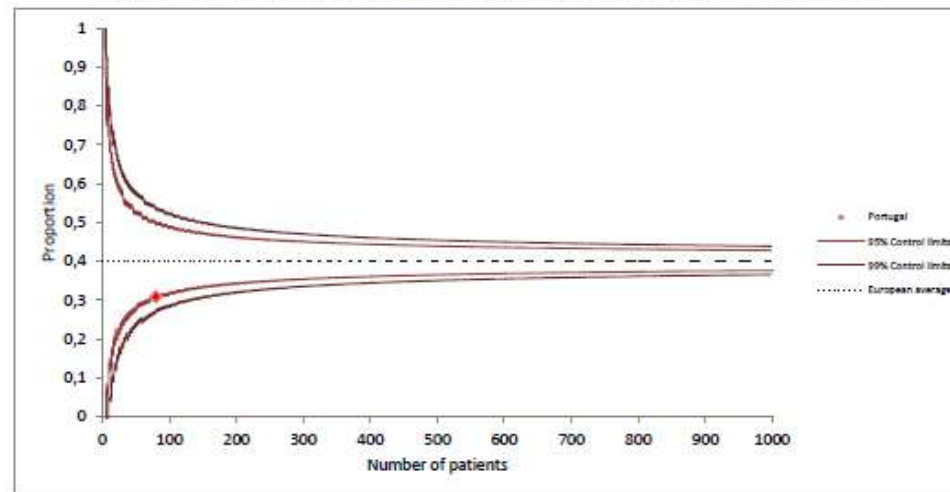
Benchmarking Report

Age-adjusted height Z-score below -2

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

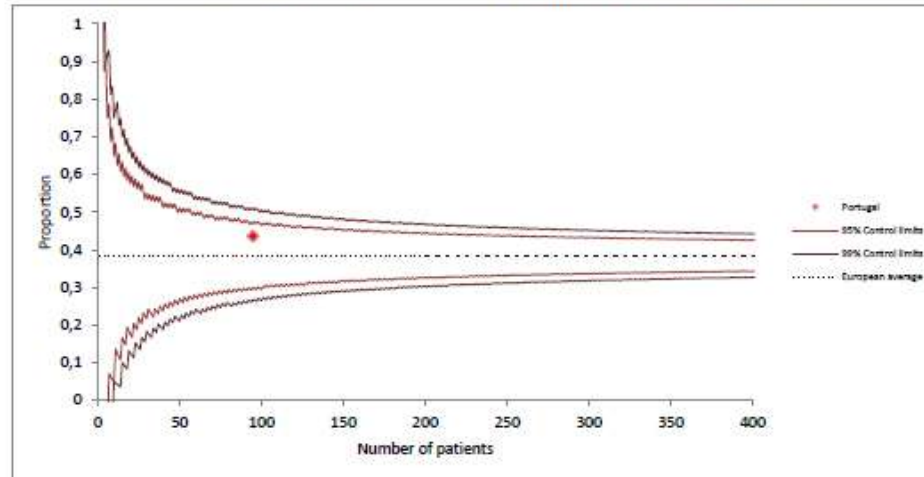


Ponto vermelho Portugal

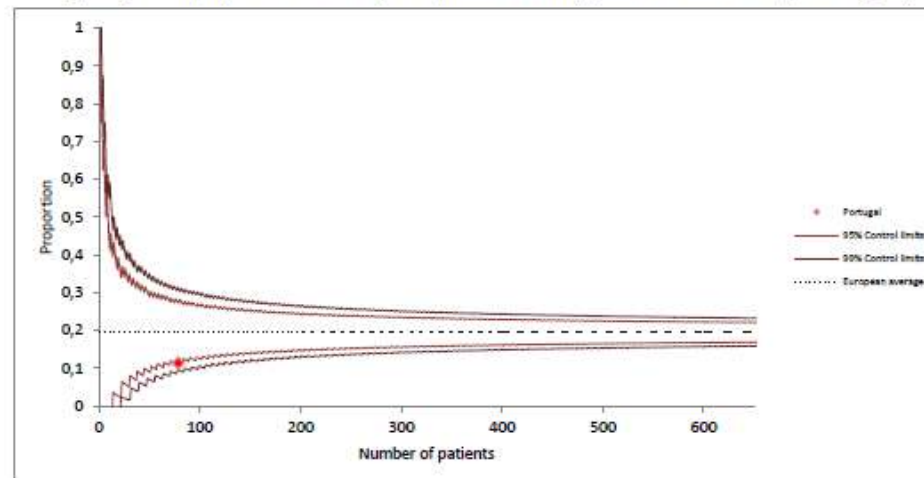
Benchmarking Report

Age-adjusted proportion of patients with hypercholesterolemia

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



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

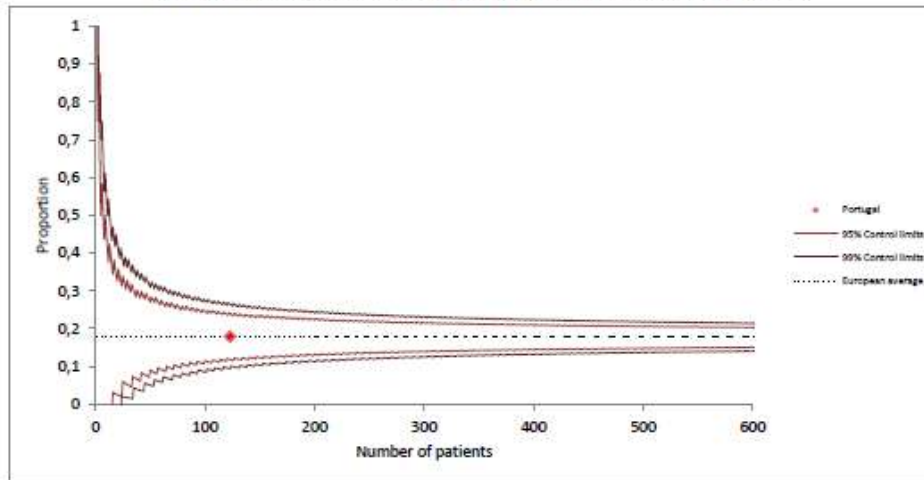


Ponto vermelho Portugal

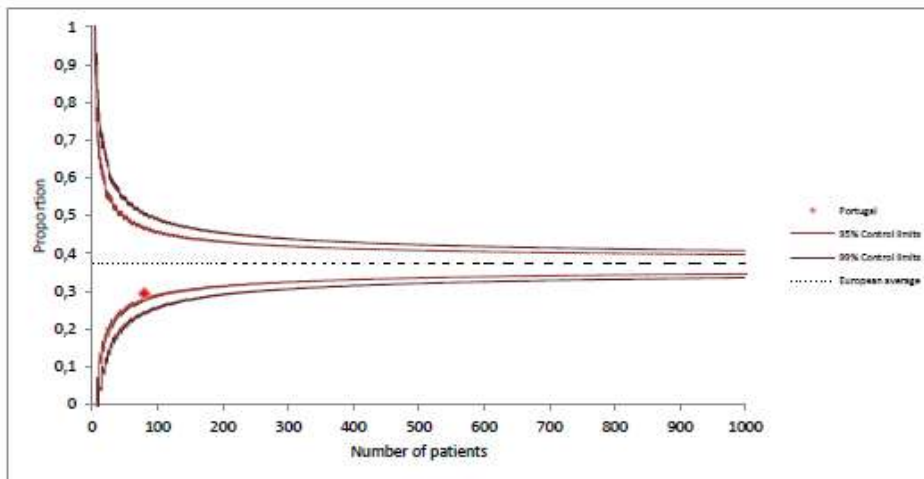
Benchmarking Report

Age-adjusted proportion of patients with overweight

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

Ponto vermelho Portugal

Publicações da ESPN/ERA-EDTA (co-autoria 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.

Publicações da ESPN/ERA-EDTA (co-autoria de nefrologistas portugueses 2015)

• **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.**

• [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](#)
[Clin J Am Soc Nephrol](#). 2015 May 7;10(5):767-75. doi: 10.2215/CJN.06200614.

• **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.**

• [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](#).
[Nephrol Dial Transplant](#). 2015 Apr 28. pii: gfv105. [Epub ahead of print]

Publicações da ESPN/ERA-EDTA (co-autoria de nefrologistas portugueses 2016)

• ***Infants requiring maintenance dialysis: outcomes of hemodialysis and peritoneal dialysis.*** Accepted by *Am J Kidney Dis*.

• ***Mortality risk disparities in children receiving chronic renal replacement therapy for the treatment of end-stage renal disease across Europe. An ESPN/ERA-EDTA Registry analysis.*** Chesnaye NC, Schaefer F, Bonthuis M, Holman R, Baiko S, Baskin E, Bjerre A, Berbeca O, Cloarec S, Cornelissen EAM, Espinosa L, Heaf JG, Stone R, Shtiza D, Zagozdzon I, Harambat J, Jager KJ, Groothoff JW, van Stralen KJ. Accepted by *The Lancet*.