

Registo da DRC5 em TSFR 2016

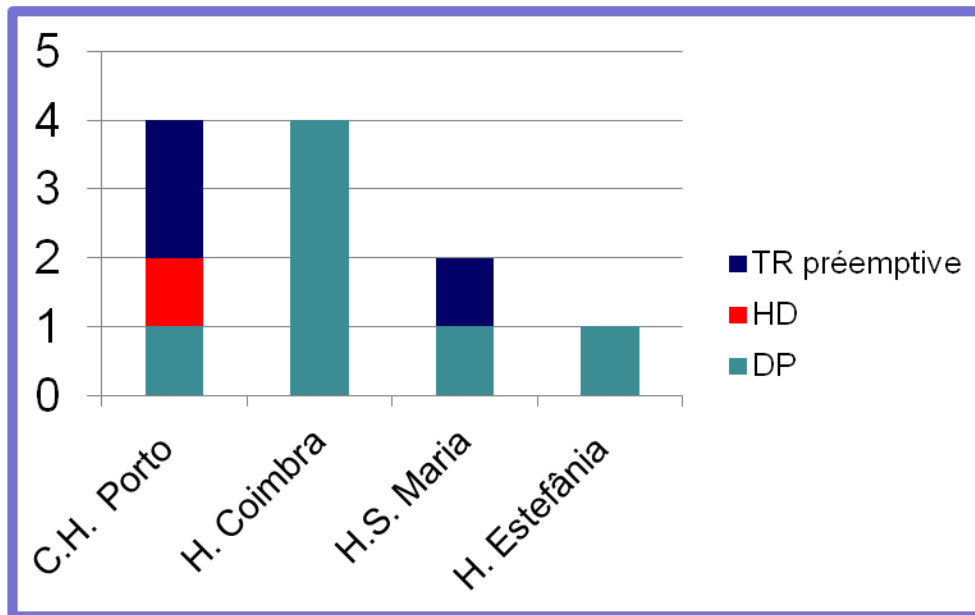


- **Fonte: Registo enviado anualmente para *European Society of Pediatric Nephrology (ESPN)*, com a contribuição das Unidades de Nefrologia Pediátrica Portuguesa.**
- Conceição Mota (C.H.Porto)
- Rosário Stone (H.S. Maria, Lisboa)
- Margarida Abranches (H. D. Estefânia, Lisboa)
- Clara Gomes (H. Pediátrico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

Doentes que iniciaram TSFR no ano de 2016

N=11

4 género feminino; 7 género masculino

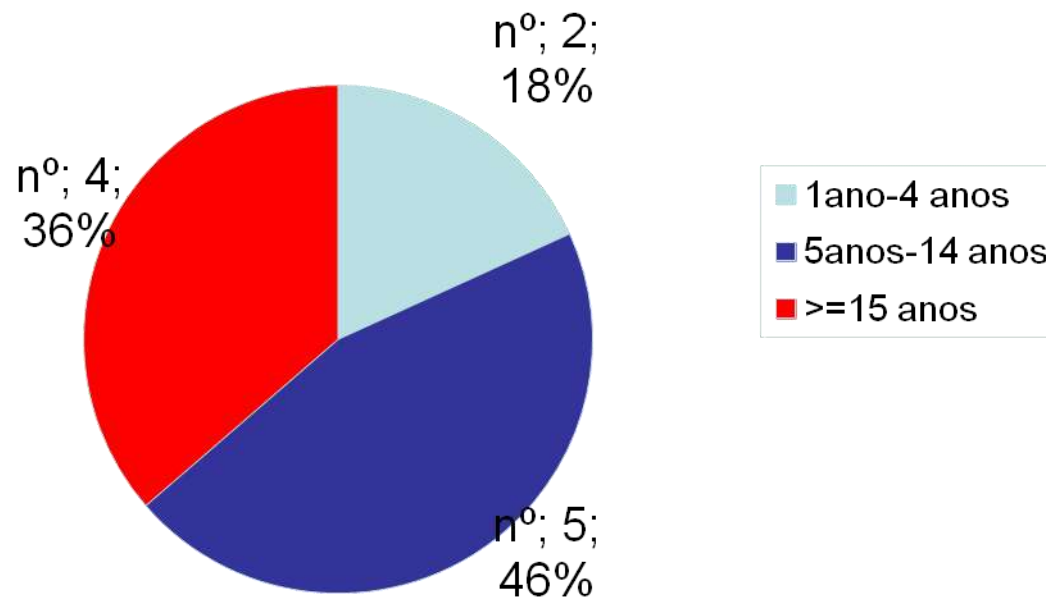


Tipo de TSFR (dia1)
7em DP
1 em HD
3 TR préemptive.

Idade à data da 1º TSFR

Doentes incidentes em 2016

Média=10,7± 5,7 anos



Movimento -ano de 2016-

<i>IN</i>	
Novos doentes	11

<i>OUT</i>	
Número de TR	15
Mortos	2
Recuperação da FR	0
Saída de registo → transferência adultos	14

<i>Mudança de TSFR</i>	
DP → HD	3
HD → DP	0
TR → HD	1

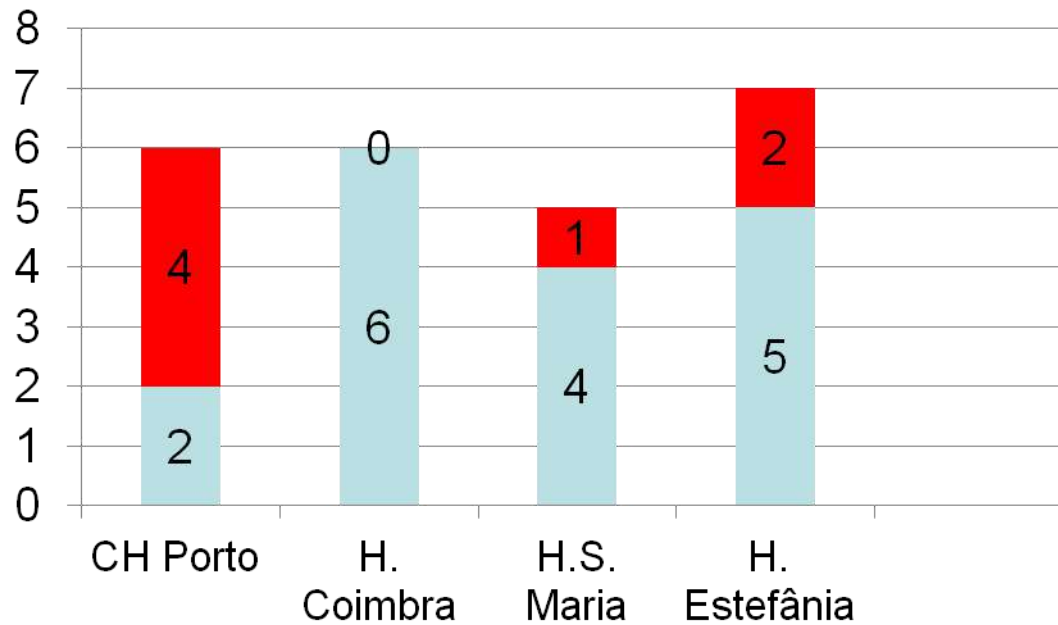
Doentes pediátricos que foram transplantados no ano de 2016

N=15 transplantes

- Centro Hospitalar do Porto; n=2
 - Hospitais Universitários de Coimbra/Pediátrico; n=5
 - H. S. Maria, Lisboa; n=8
-
- Dador. Rim de dador cadáver; n=12
 - Dador Rim de dador vivo; *préemptive*. n= 3
 - Transplantados com sucesso; n=15

Prevalência pontual de doentes em diálise em ambiente pediátrico (31/12/2016)

N=24

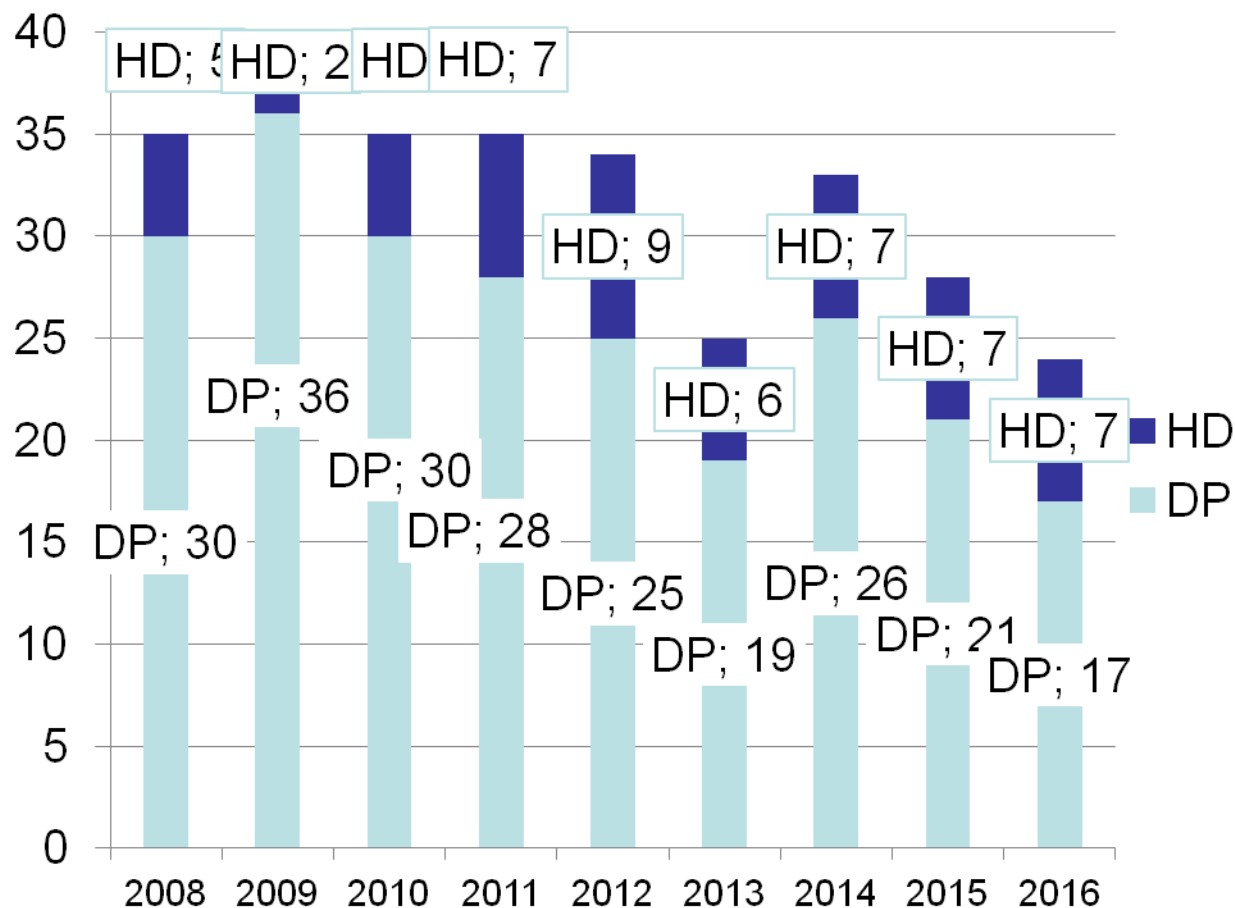


DP=17(75%)
HD=7(25%)

■ HD
■ DP

Evolução do registo

Prevalência pontual de doentes em diálise
a 31 /12/2016



Prevalência pontual de doentes com transplante renal
(enxerto funcionante) com seguimento em
Unidades de Nefrologia Pediátrica a 31/12/2016

N=94

H S Maria-Lisboa	50
C Hospitalar Porto	31
H Pediátrico Coimbra	13

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

(31/12/2016)

n=118

Malformações do rim e tracto urinário (CAKUT)	52 (48,5%)
Glomerulonefrite e glomerulosclerose	19 (17,1%)
Doenças quísticas hereditárias	6 (5,7%)
Doenças metabólicas e tubulo-intersticiais	12(10,4%)
Toxico-isquémicas	8 (6,6%)
Síndrome hemolítico urémico (códigos 88)	8(6,6%)
Vascular	-
Outras	7(6,1%)
Desconhecida	6(5,7%)

Incidência de doentes com idade inferior a 15 anos em TSFR

	Incidência (0-18 anos) Nº Portugal	Incidência (0-14 anos) Nº Portugal	Incidência (0-14 anos) pmart ⁽¹⁾ Portugal	Incidência (0-14 anos) pmart Europa
2007	19	16	9,8	ND ⁽²⁾
2008	16	13	7,9	ND
2009	18	15	9,3	ND
2010	17	11	6,7	ND
2011	18	15	9,5	4,4
2012	24	16	10,2	3,9
2013	11	7	4,6	4,7
2014	17	13	8,6	5,4
2015	16	10	6,4	6,0
2016	11	7	4,7	.ND

⁽¹⁾pmart=per million of the age –related population)

⁽²⁾ND- Não determinada

Prevalência pontual de Doentes Pediátricos em TSFR

Ano	Prevalência (0-14 anos) Nº Portugal	Prevalencia (0-14 anos) Pmart Portugal	Prevalencia) (0-14 anos) pmart Europa	Prevalencia 0-19 anos (pmart Portugal
31/12/2007	64	39,2	ND	ND
31/12/2008	56	34,4	ND	ND
31/12/2009	70	43,2	ND	ND
31/12/2010	77	47,1	ND	ND
31/12/2011	77	49,1	26,1	ND
31/12/2012	84	53,8	32,6	91,1
31/12/2013	78	50,8	29,7	80,2
31/12/2014	79	52,5	38,8	84,9
31/12/2015	80	54,2	35,5	92,8
31/12/2016	77	49,1	ND	84,9

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
2016	11	15

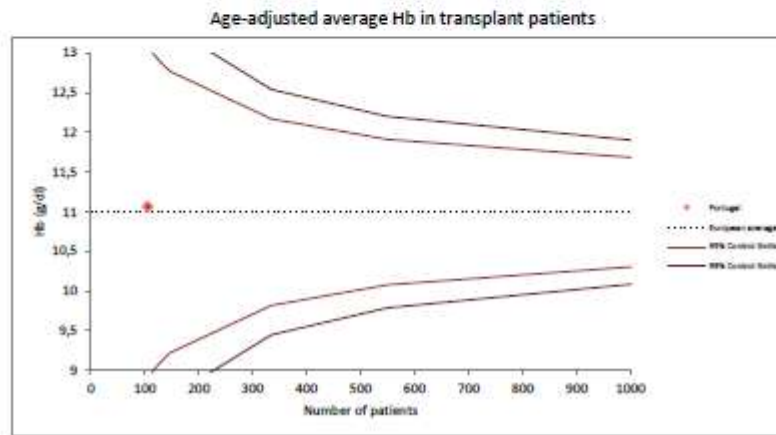
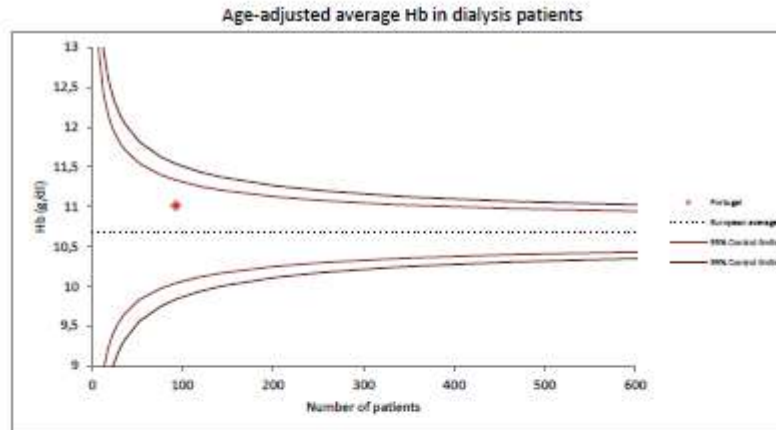
Preliminary Benchmarking Report

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 2017 pelo
ESPN registry,
Comparação de Portugal com a média de todos os 36 países
europeus que contribuem para o registo da ESPN

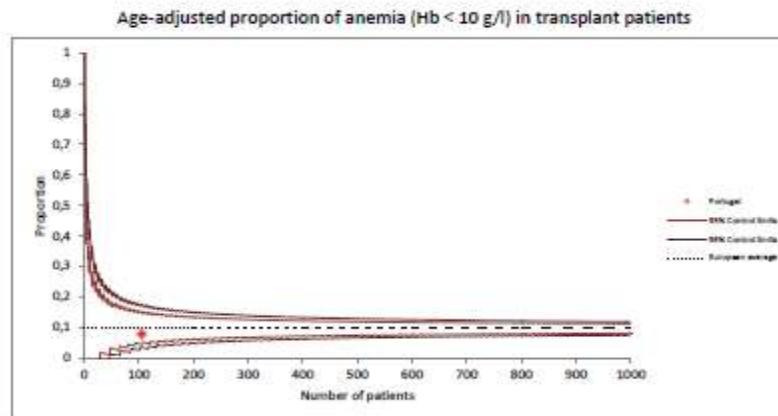
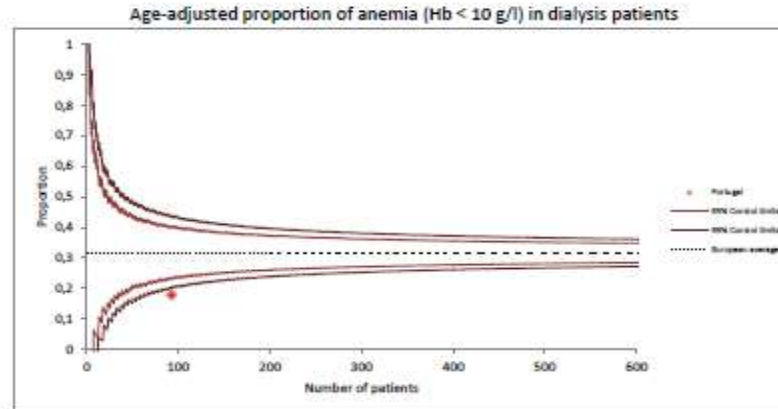
Benchmarking Report

Age-adjusted average Hb



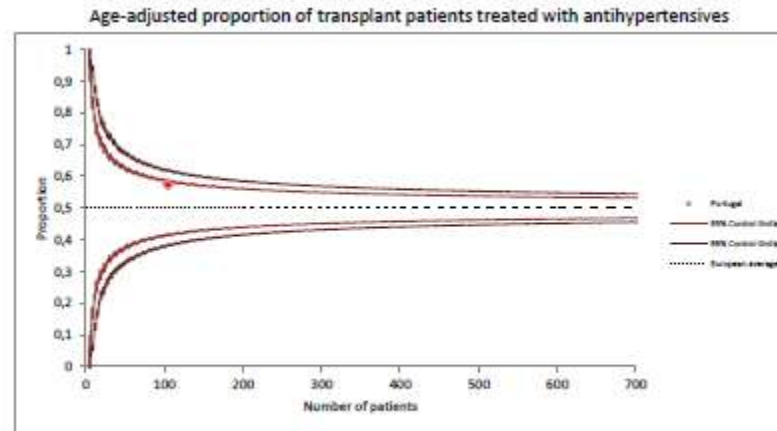
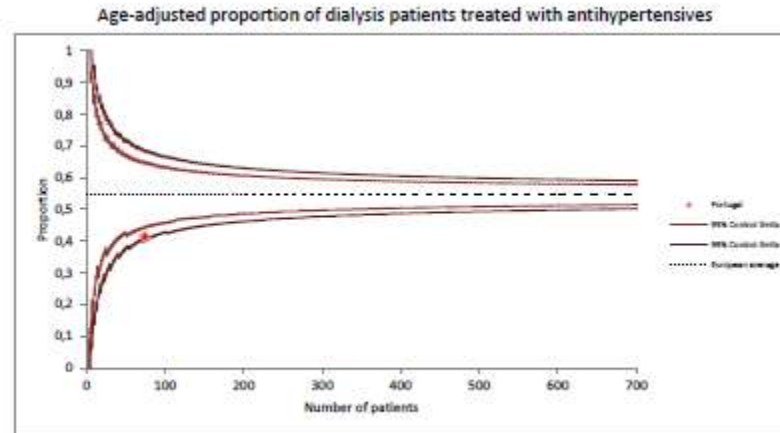
Benchmarking Report

Age-adjusted proportion of anemia



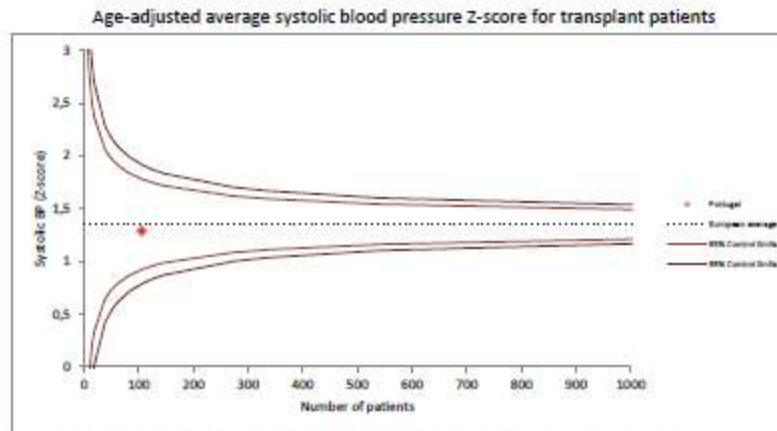
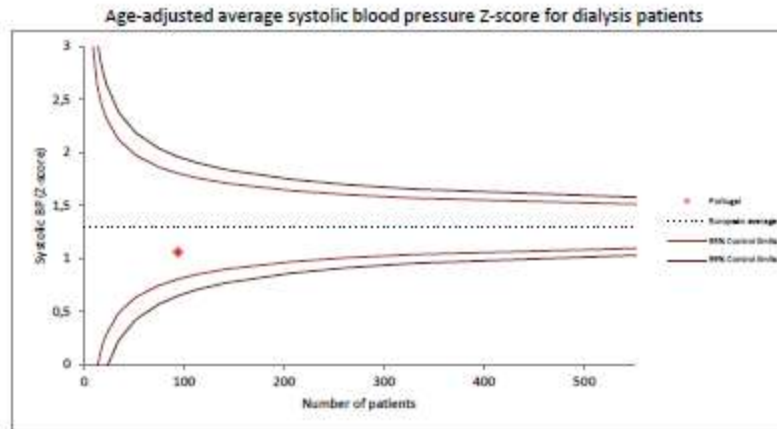
Benchmarking Report

Age-adjusted patients treated with antihypertensives



Benchmarking Report

Age-adjusted average systolic blood pressure Z-score

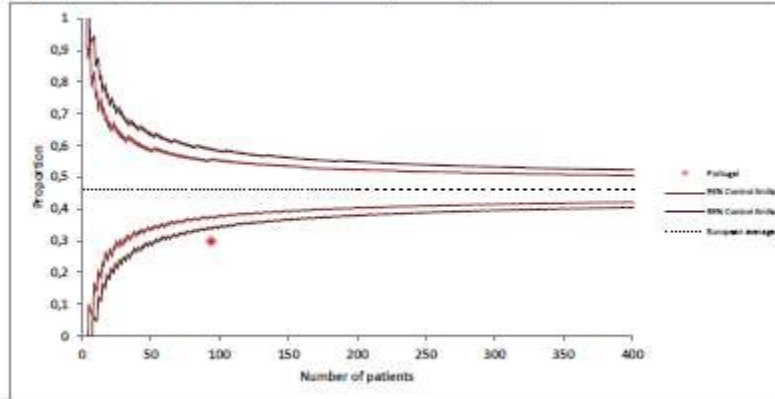


Blood pressure SDS was calculated following the fourth report of the National High Blood Pressure Education Program (NHBPEP) (National High Blood Pressure Education Program Working Group on High Blood Pressure in Children and Adolescents. The fourth report on the diagnosis, evaluation, and treatment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

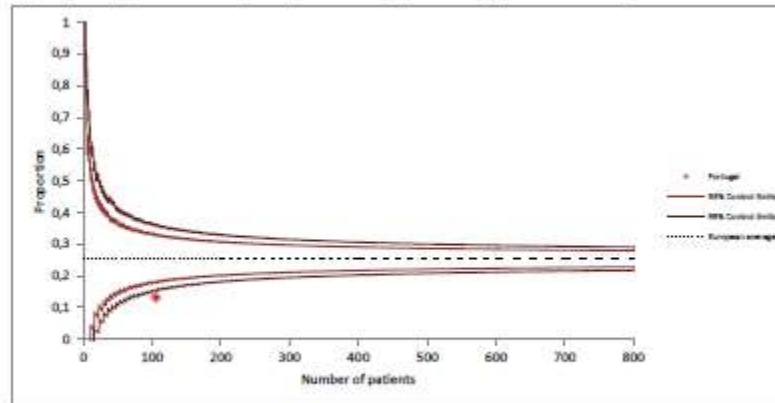
Benchmarking Report

Age-adjusted average diastolic blood pressure Z-score

Age-adjusted 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)

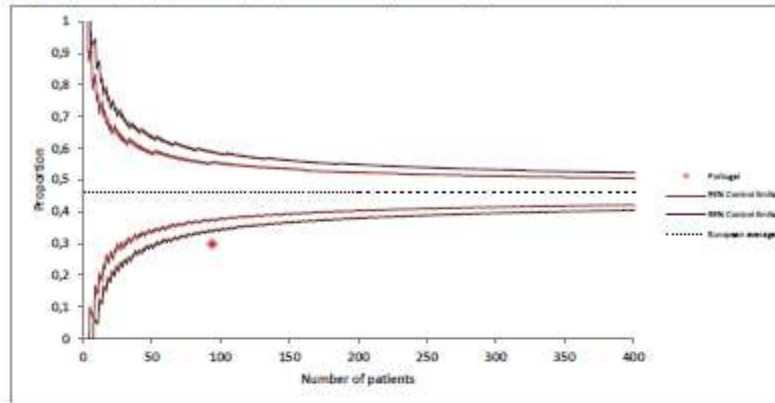


Ponto vermelho Portugal

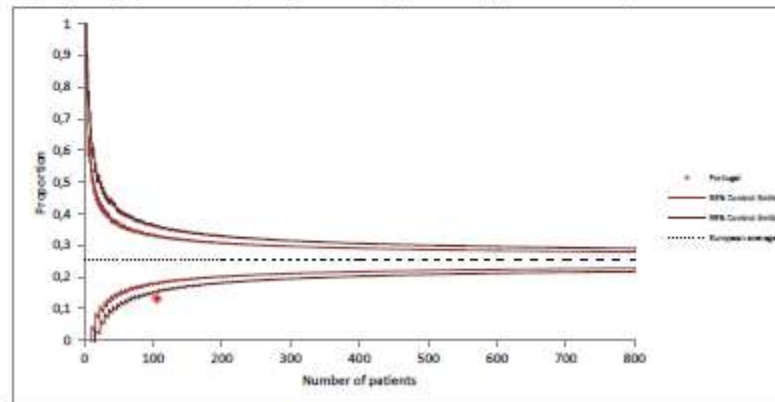
Benchmarking Report

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

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

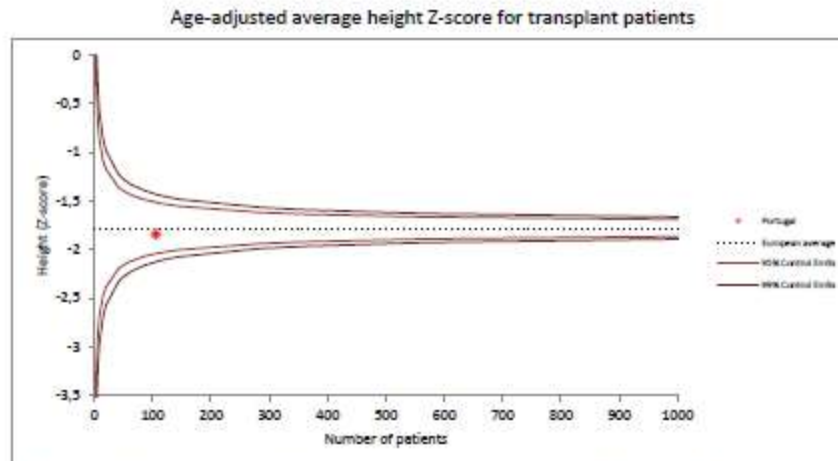
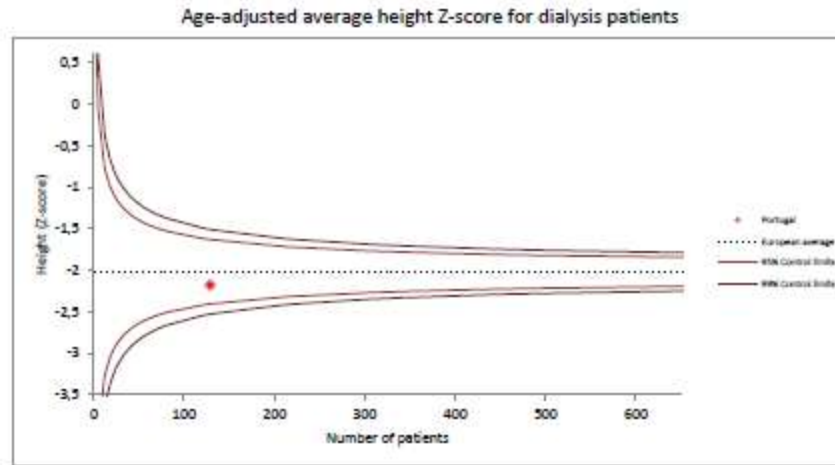


Age-adjusted proportion of transplant patients with hypertension (systolic or diastolic pressure Z-score > 1.64)



Benchmarking Report

Age-adjusted average height Z-score

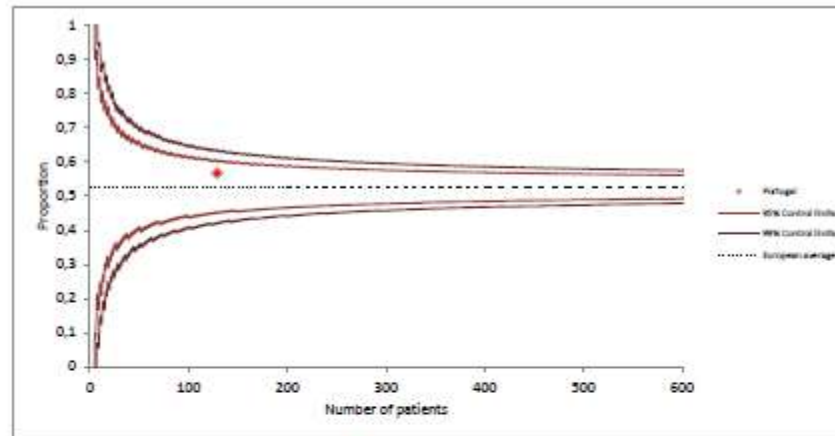


Height SDS was calculated according recent national or European growth charts (Bonthuis et al. Use of National and international growth charts for studying height in European children: development of up-to-date European height-for-age charts. PLoS ONE 2012; 7(8): e42506)

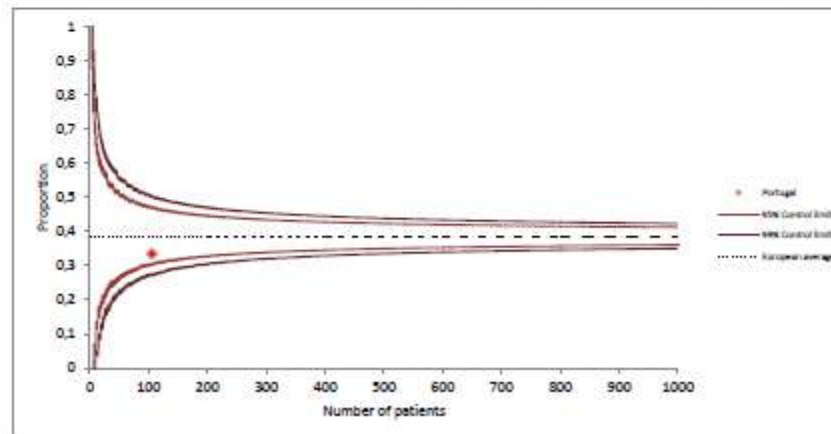
Benchmarking Report

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



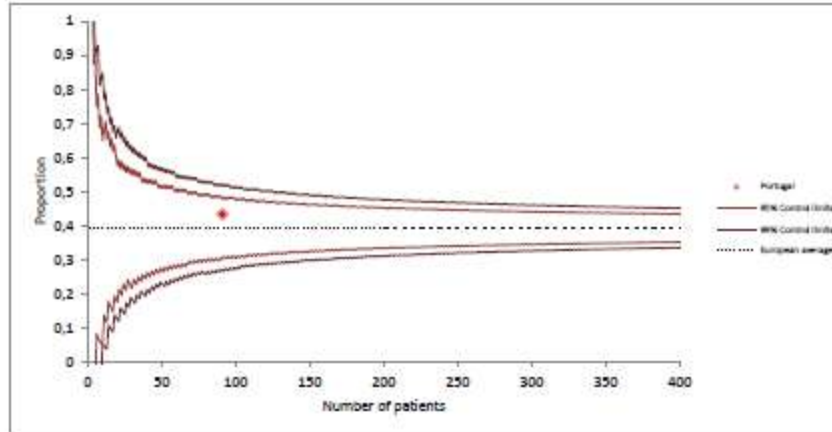
Ponto vermelho Portugal

Benchmarking Report

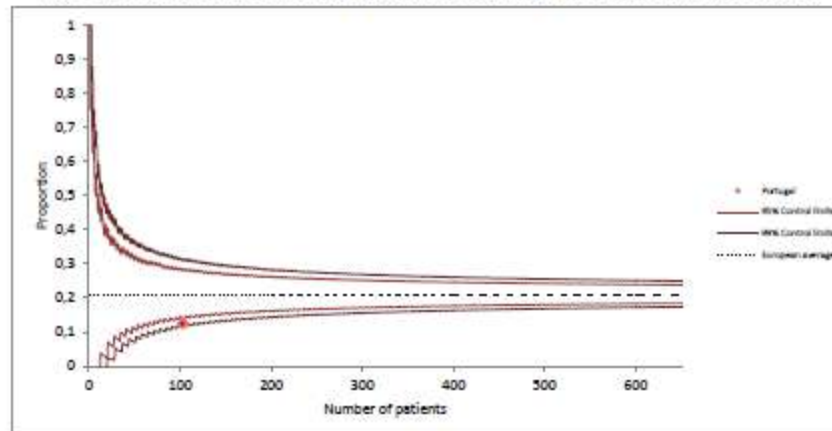
Age-adjusted proportion of patients with hypercholesterolemia

Preliminary Benchmarking Report

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



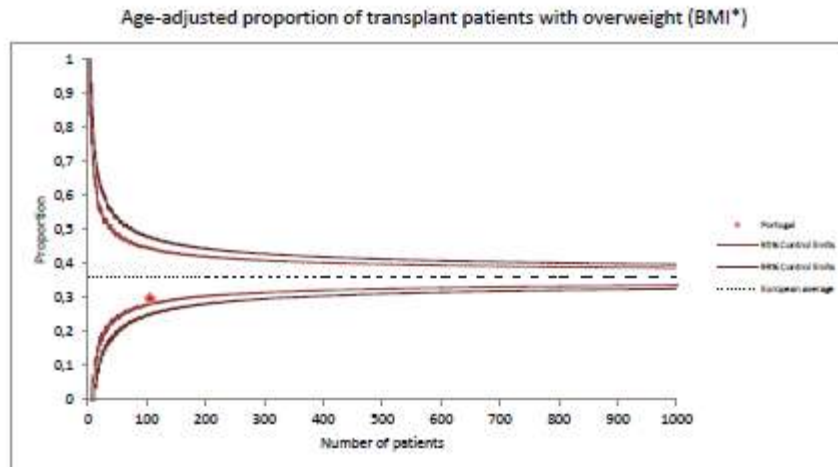
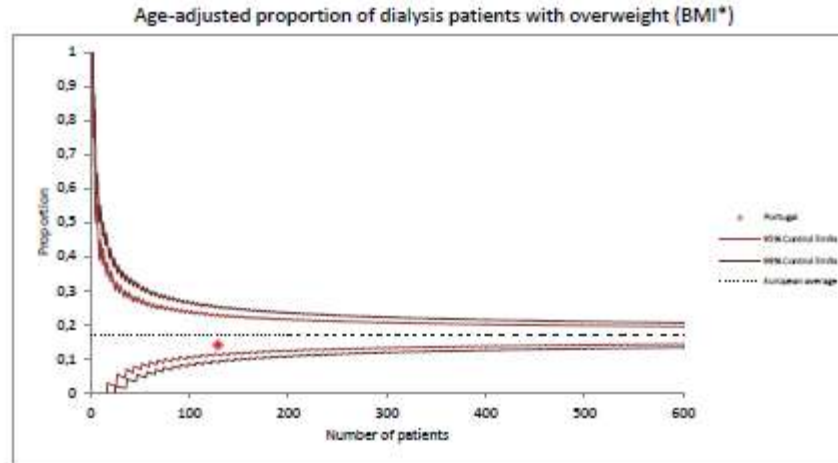
Age-adjusted proportion of transplant patients with hypercholesterolemia (>200 mg/dl)



Ponto vermelho Portugal

Benchmarking Report

Age-adjusted proportion of patients with overweight



* 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

(coautoria nefrologistas pediátricos 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, Jankauskienė 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, Zagozdzon 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, Zagozdzon 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

(coautoria de nefrologistas portugueses 2015-2017)

• **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.

• **Infants requiring maintenance dialysis: outcomes hemodialysis and peritoneal dialysis.** Vidal E, van Stralen KJ, Chesnaye NC, Bonthuis M, Holmberg C, Zurowska A, Trivelli A, [Eduardo Esteves Da Silva J](#), Herthelius M, Adams B, Bjerre A, Jankauskiene A, Miteva P, Emirova K, Bayazit AK, Mache JC, Sánchez-Moreno A, Harambat J, Groothoff JW, Jager KJ, van Stralen KJ, Bonthuis M, Groothoff JW, Harambat J Schaefer F, Verrina E. *Am J Kidney Dis.* 2017 May;69(5):617-625.

• **Mortality risk disparities in children receiving 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, Cloarec S, Cornelissen EAM, Espinosa L, Heaf JG, [Stone R](#), Shtiza D, Zagazdzon I, Harambat J, Jager KJ, Groothoff JW, van Stralen KJ. *Lancet.* 2017 May; 389(10084):2128-2137.