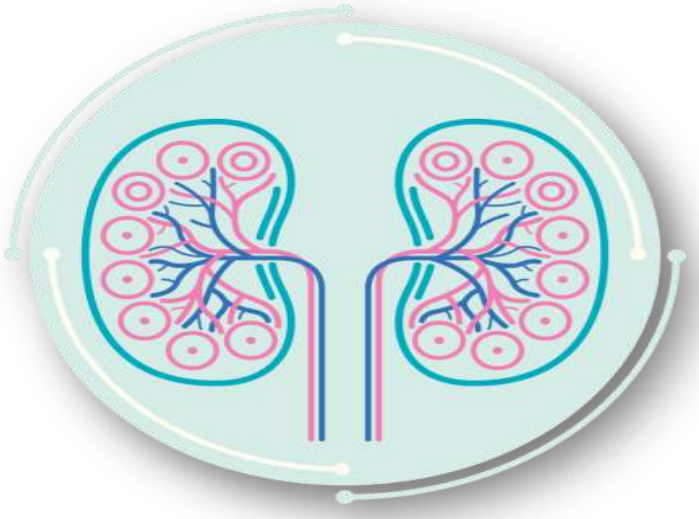
SPNP
Sociedade Portuguesa de Nefrologia Pediátrica

Registo da Doença Renal Crónica Estadio 5 em Terapêutica Substitutiva da Função Renal

Conceição Mota

(2019)



Registo da DRC5 em TSFR 2019

SPNP
Sociedade Portuguesa de Nefrologia Pediátrica

- **Fonte: Registo enviado anualmente para *European Society of Pediatric Nephrology (*ESPN), com a contribuição das Unidades de Nefrologia Pediátrica Portuguesa.**

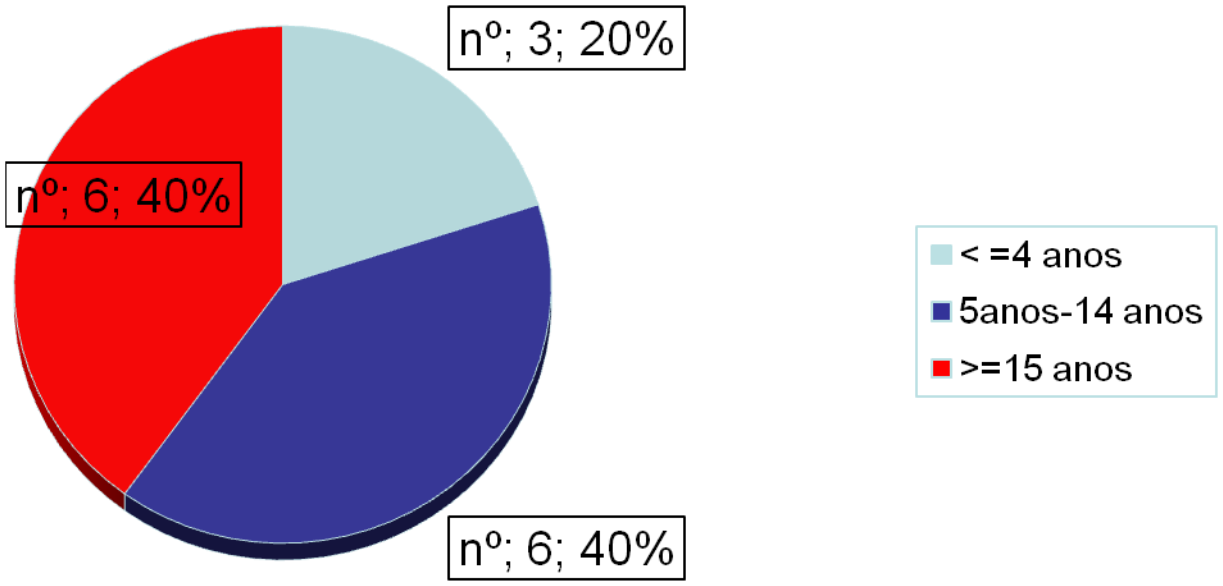
- Conceição Mota (C.H.Porto)
- Rosário Stone (H.S. Maria, Lisboa)
- Margarida Abranches (H. D.Estefânia, Lisboa)
- Clara Gomes (H. Pediátrico de Coimbra)

Doentes Incidentes em 2019 (1º TSFR)

15 doentes

Idade Média=11,4± 5,7anos

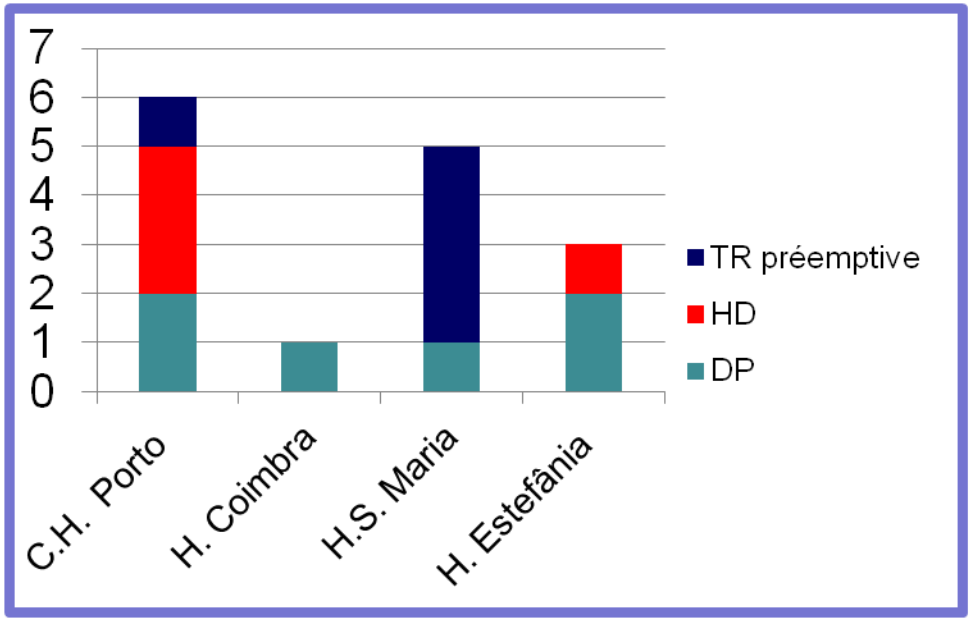
Género 9 M/6F;
12 caucasianos/3 negros



Doentes que iniciaram TSFR 2019

ANO 2019
Tipo de TSFR (dia1)
6 em DP
4 em HD
5 TR *préemptive*.

N=15



Doentes pediátricos que foram transplantados

2019

N=10 transplantes

- **Centro Hospitalar do Porto; n=4**
- **H. S. Maria, CH Lisboa Norte; n=6**

- Dador: Rim de dador cadáver n=7; dador vivo n=3
- TR *préemptive*. n= 5

Movimento
-ano de 2019-

IN	
Novos doentes em RRT	15
Novos doentes (transferidos em RRT. Estrangeiro→ Portugal	2

OUT	
Número de TR	10
Mortos	1
Recuperação da FR	0
Saída de registo→ transferência “Adultos”	17

Mudança de TSFR	
TR→HD	-
HD→DP	1
DP→HD	2

Prevalência pontual de doentes com transplante renal (enxerto funcionante) com seguimento em Unidades de Nefrologia Pediátrica a 31/12/2019

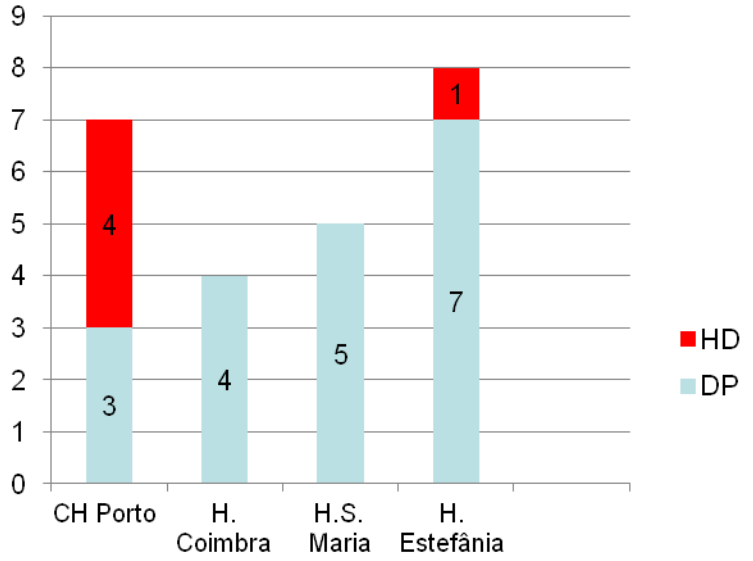
N=82

H S Maria-Lisboa	47
C Hospitalar Porto	27
H Pediátrico Coimbra	8

Prevalência pontual de doentes em diálise em ambiente pediátrico

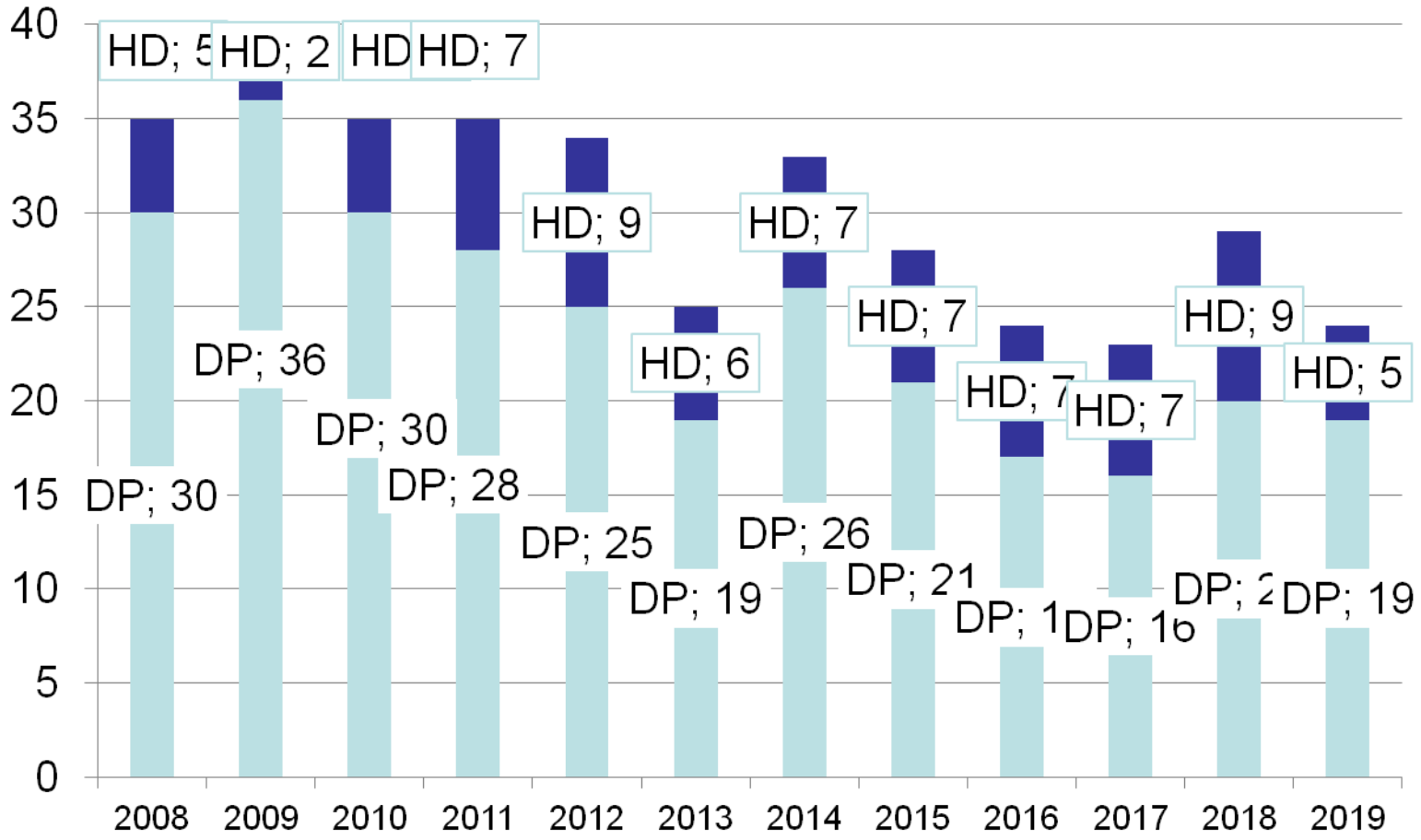
N=24

DP=19 (79,2%)
HD=5 (20,8%)



Evolução do registo

Prevalência pontual de doentes em diálise a 31 de Dezembro



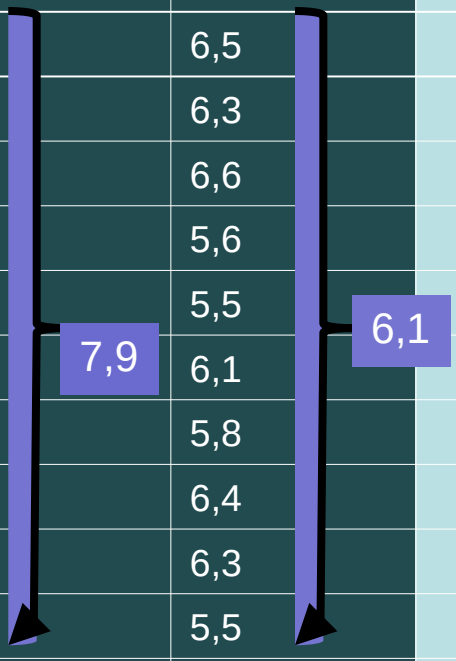
Evolução do registo

Ano	Novos doentes	Transplante/ ano
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
2017	13	13
2018	14	6
2019	15	10

Incidência de doentes com idade pediátrica em TSFR

(1)pmart=per million of the age –related population) 1451624

	Incidência (0-14 anos) pmart(1) Portugal	Incidência (0-14 anos) pmart Europa	Incidência (0-18 anos) Nº Portugal
2007	9,1	6,5	
2008	7,3	6,3	16
2009	10,5	6,6	18
2010	5,0	5,6	17
2011	9,5	5,5	18
2012	12,2	6,1	24
2013	4,6	5,8	11
2014	8,6	6,4	17
2015	6,8	6,3	16
2016	4,8	5,5	11
2017	7,9	6,1	13
2018	5,5	ND	14
2019	6,2	ND	15



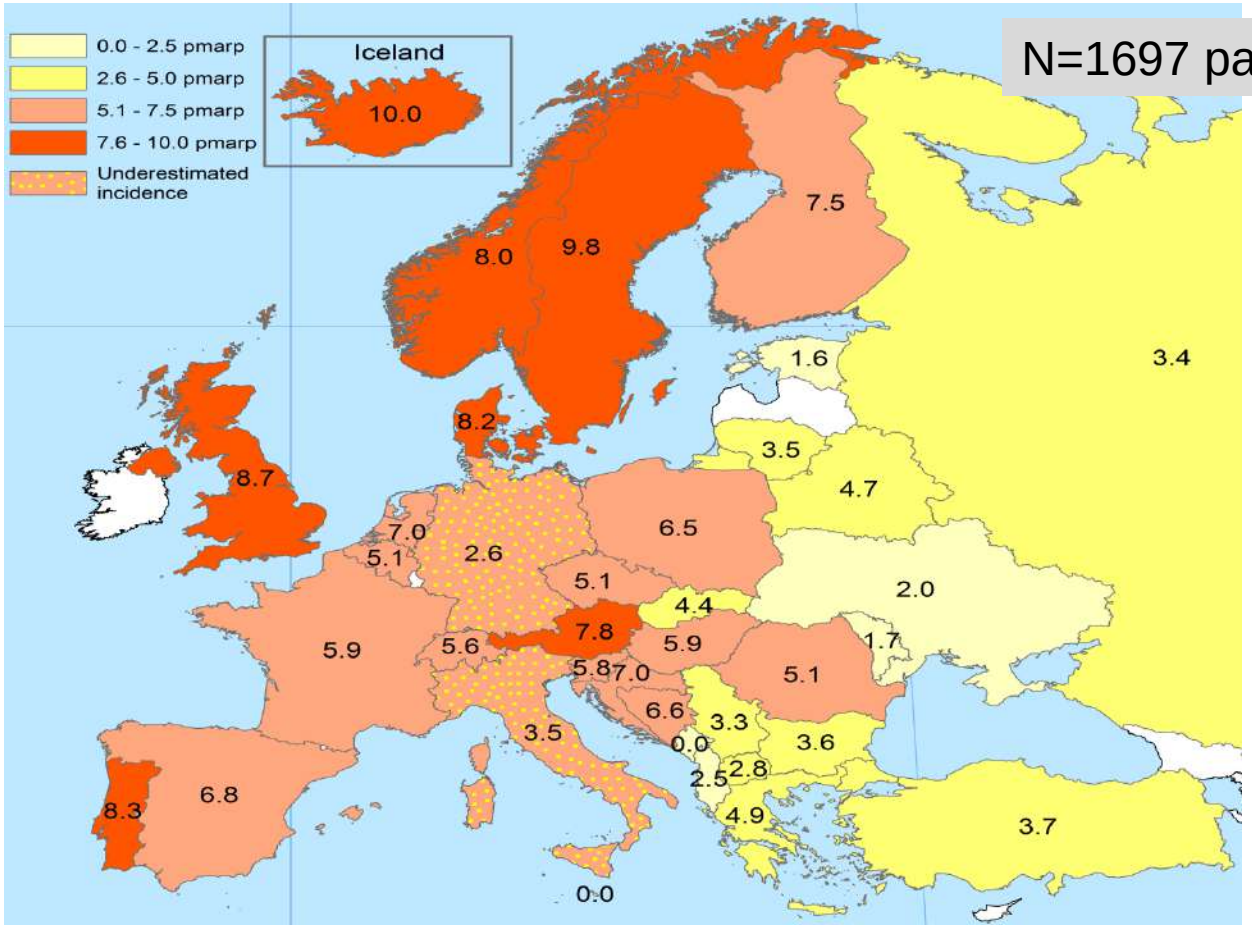
Prevalência pontual de Doentes Pediátricos em TSFR

Populacao 0'-14 a-1 451 624
Populaçao 0-18 a -3 084 001

Ano	Prevalencia (0-14 anos) Pmart Portugal	Prevalencia) (0-14 anos) pmart Europa	Prevalencia 0-18 anos (pmart Portugal
31/12/2007	38,2	29	-
31/12/2008	40,9	30,0	-
31/12/2009	44,9	32,4	-
31/12/2010	45,4	32,0	-
31/12/2011	50,5	32,5	-
31/12/2012	59,6	33,4	91,1
31/12/2013	54,7	33,5	80,2
31/12/2014	57,1	34,4	84,9
31/12/2015	56,3	35,3	92,8
31/12/2016	50,3	35,6	102.1
31/12/2017	52,8	ND	105,5
31/12/2018	52,5	ND	98,1
31/12/2019	50,8	ND	101,1

49,6

32,9



N=1697 patients

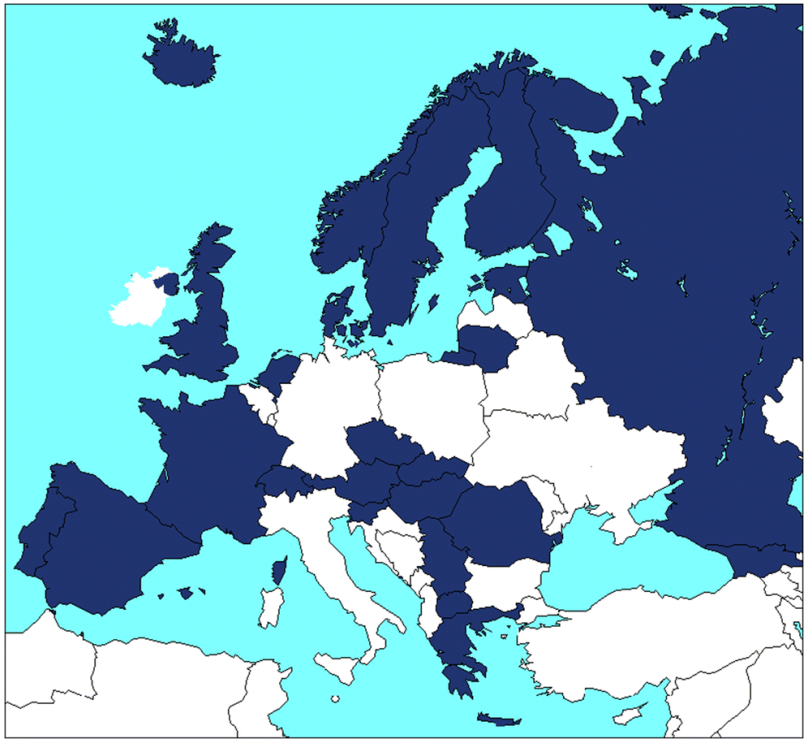
Demographics of paediatric renal replacement therapy in Europe: a report of the ESPN/ERA-EDTA registry.

Chesnaye N, Bonthuis M, Schaefer F, Groothoff JW, Verrina E, Heaf JG, Jankauskiene A, Lu-kosiene V, Molchanova EA**, Mota C**, Peco-Antic A, Ratsch IM, Bjerre A, Roussinov DL, Sukalo A, To-paloglu R, Van Hoeck K, Zagozdzon I, Jager KJ, Van Stralen KJ; Pediatr Nephrol 2014 (

Ten year trends in epidemiology and outcomes of pediatric kidney replacement therapy in Europe: data from the ESPN/ERA-EDTA Registry .

Methods: All children aged <15 years starting KRT 2007–2016 in 22 European countries, 4459 patients aged 0–14 years participating.

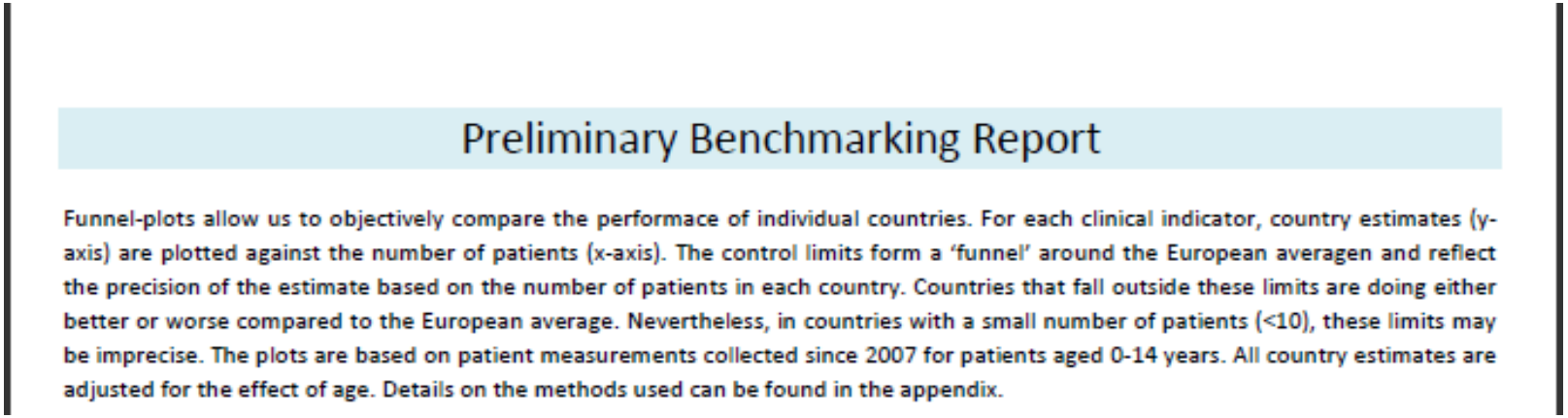
ESPN/ERA-EDTA Registry



Conclusions
We found a stable incidence and increasing prevalence of European children on KRT 2007–2016. Five-year patient survival was good and was unchanged over time

Bonthuis M et al. Pediatr Nephrol (2021).

Benchmarking Report



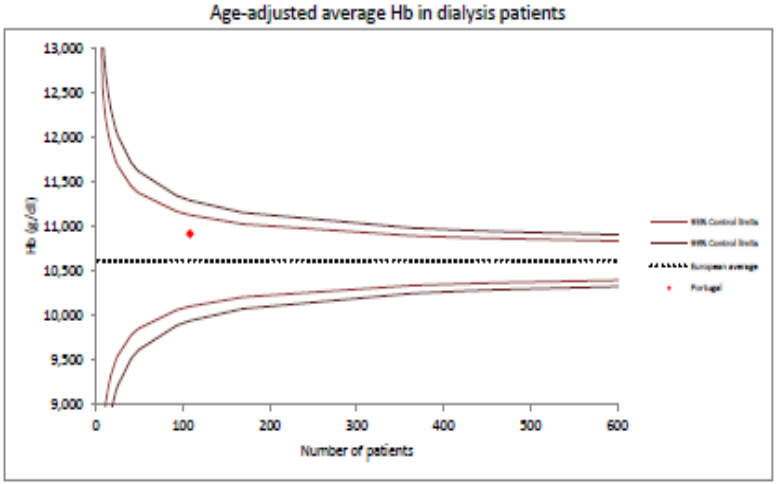
Preliminary Benchmarking Report

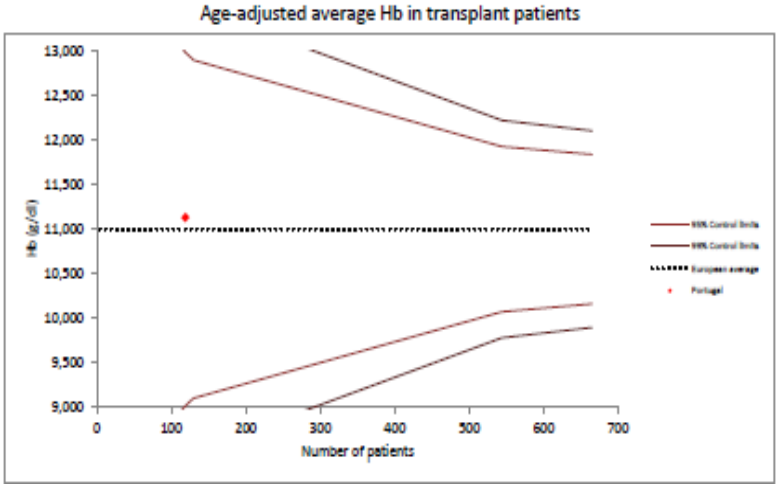
Funnel-plots allow us to objectively compare the performace of individual countries. For each clinical indicator, country estimates (y-axis) are plotted against the number of patients (x-axis). The control limits form a 'funnel' around the European averagen and reflect the precision of the estimate based 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 Novembro de 2020 pelo
ESPN registry
Comparação de Portugal com a média de todos os 36 países europeus que contribuem para o registo da ESPN.
Dados obtidos desde 2007.

Benchmarking Report

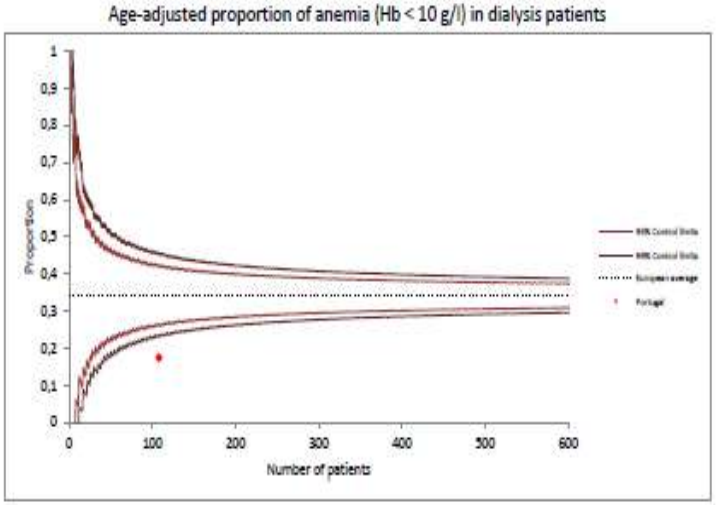
Age-adjusted average Hb

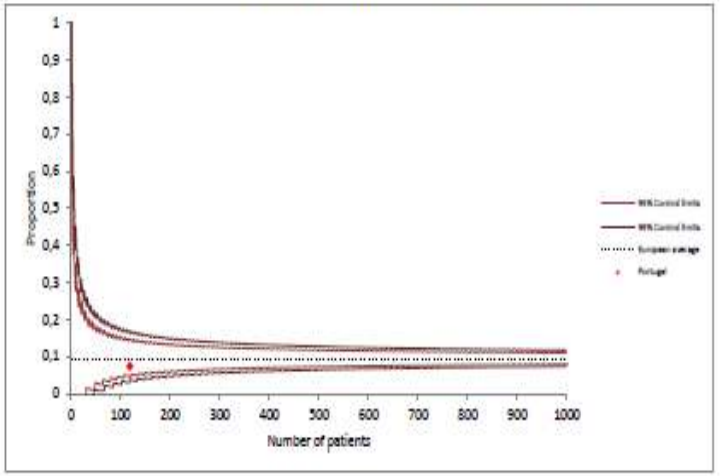




Benchmarking Report

Age-adjusted proportion of anemia

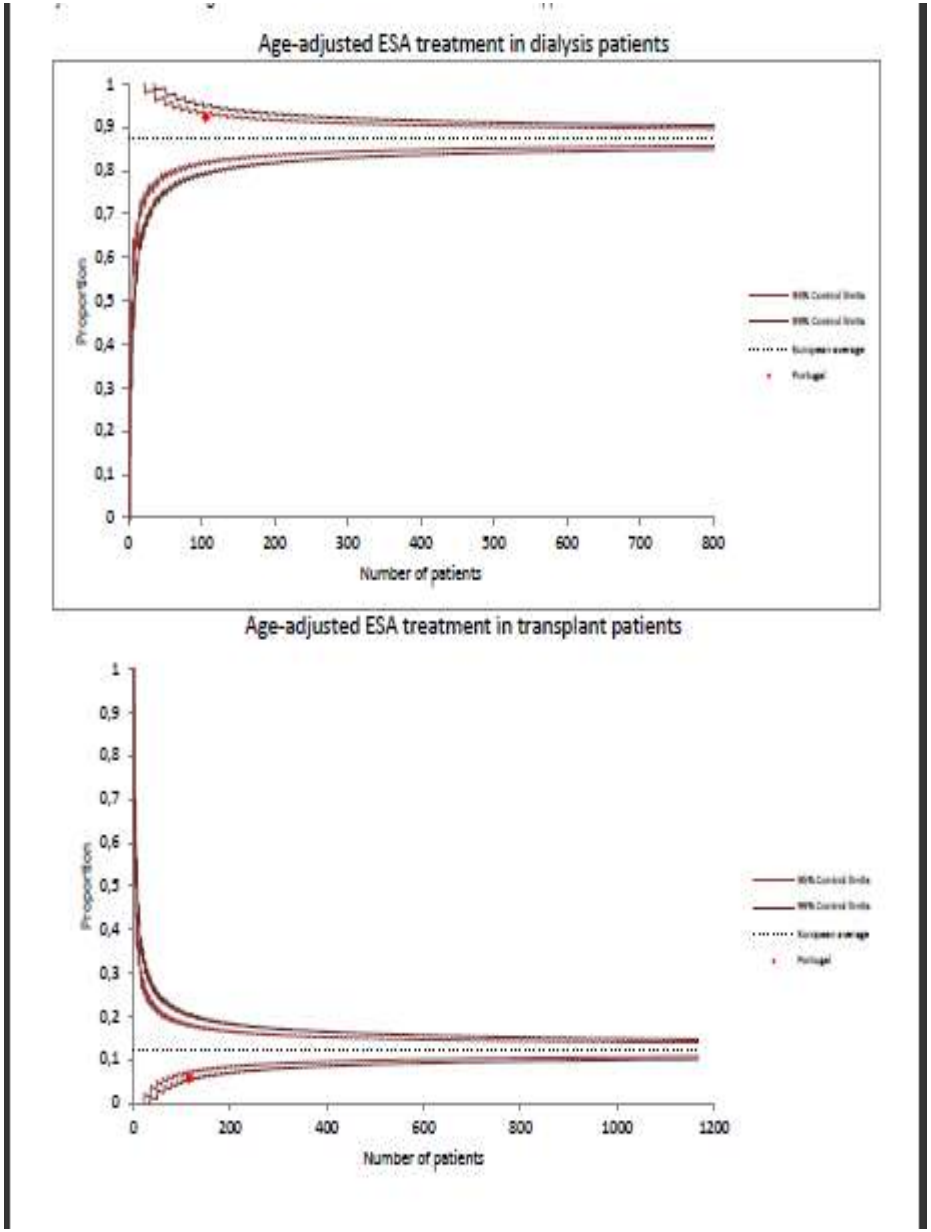




Ponto vermelho Portugal

Benchmarking Report

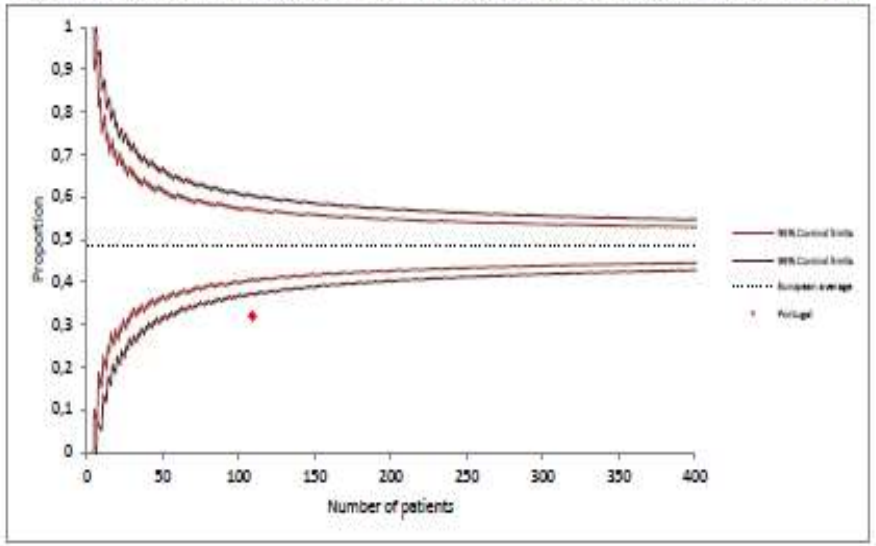
Age-adjusted ESA treatment



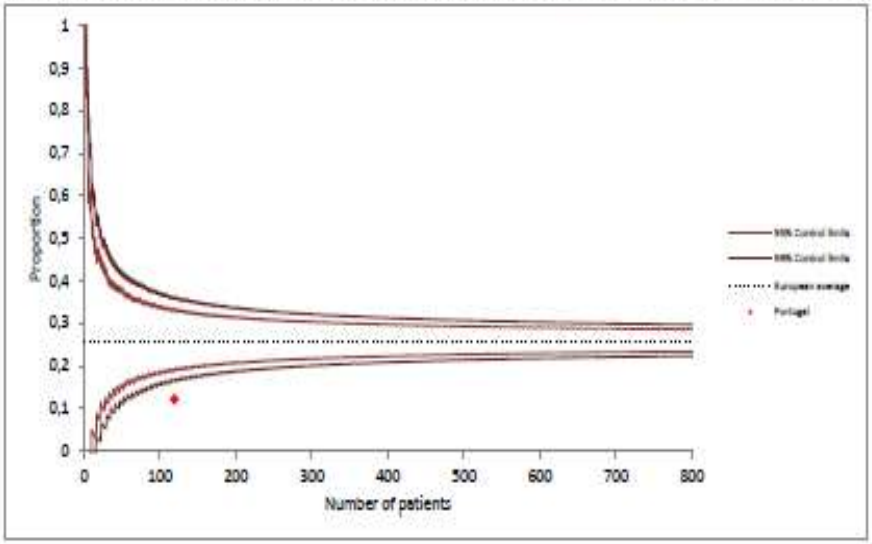
Benchmarking Report

Age-adjusted proportion of patients with hypertension (systolic or diastolic blood pressure Z-score>1,64)

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

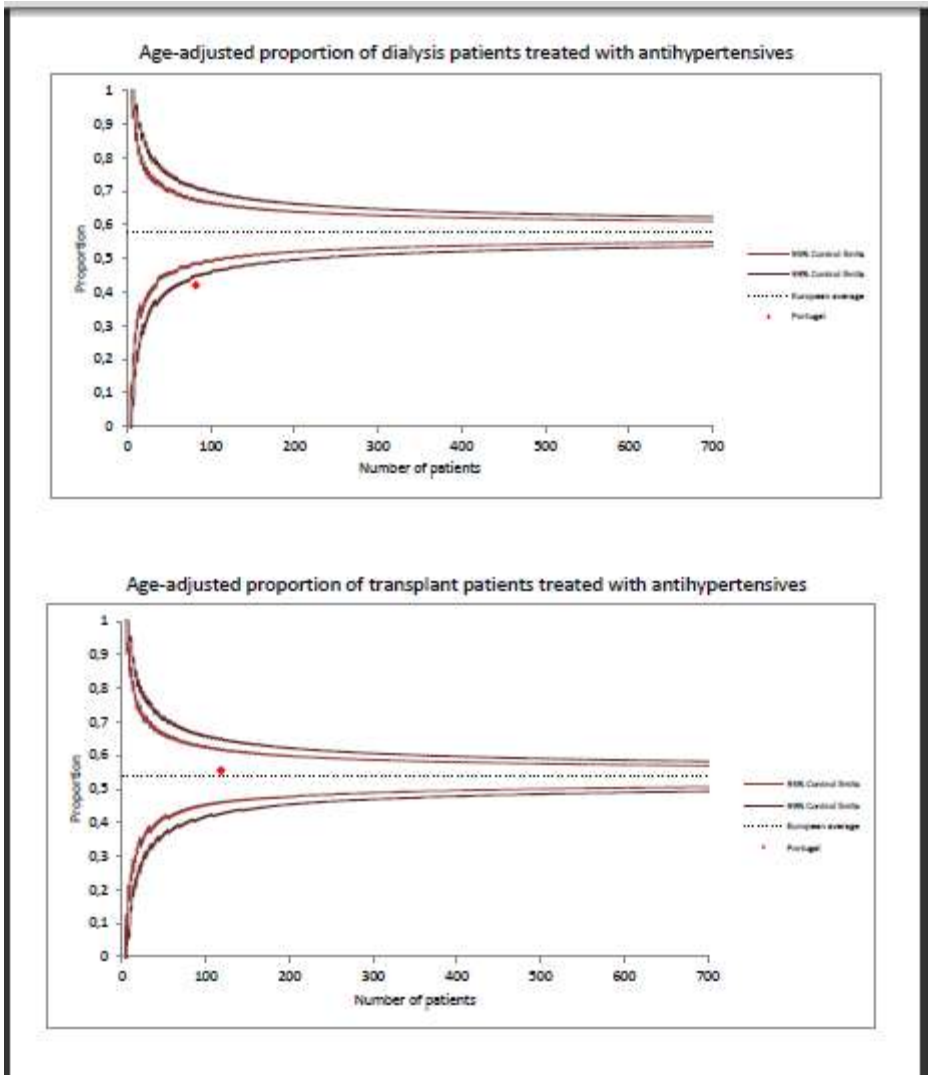


Age-adjusted proportion of transplant patients with hypertension (systolic or diastolic pressure Z-score > 1.64)



Benchmarking Report

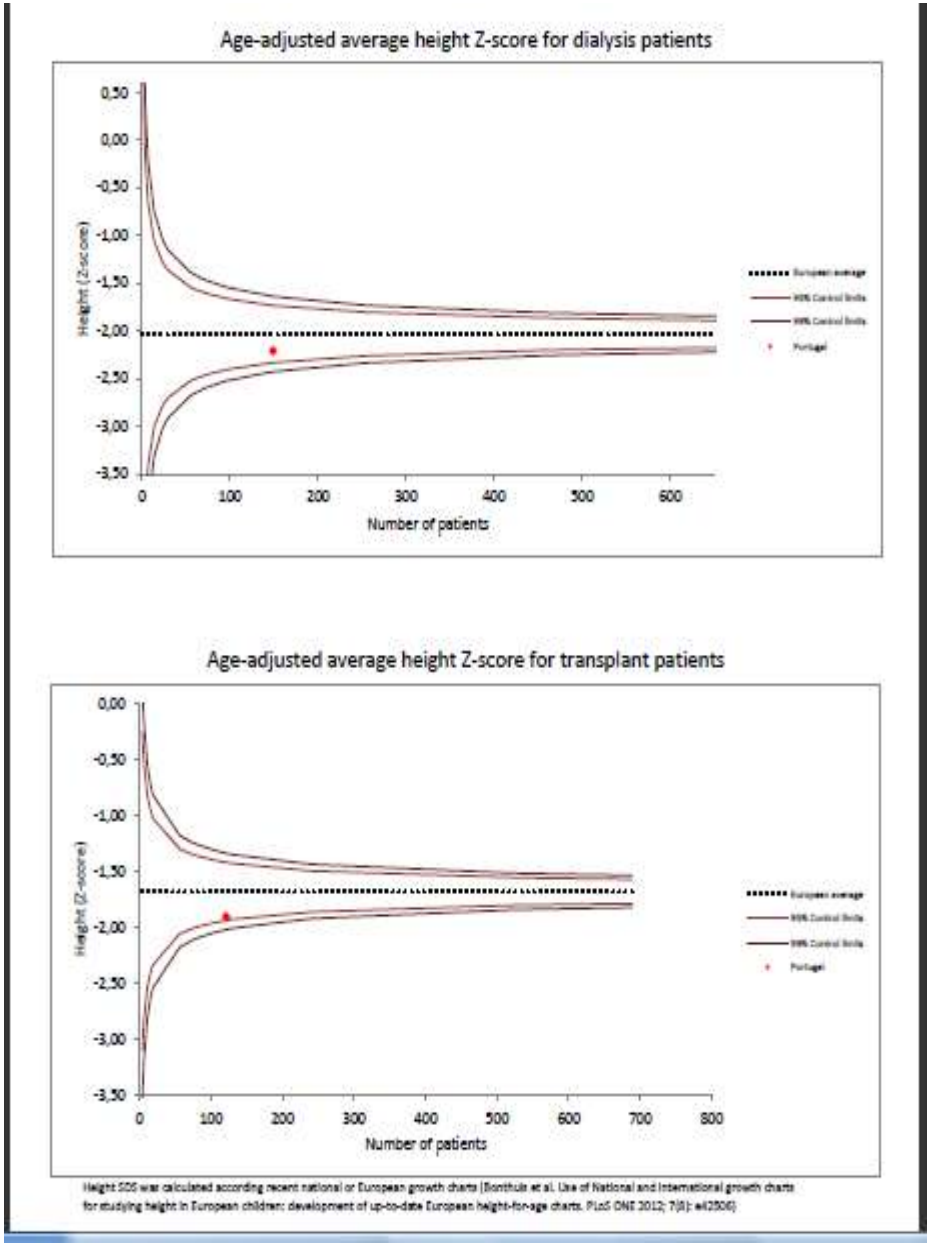
Age-adjusted patients treated with antihypertensives



Ponto vermelho Portugal

Benchmarking Report

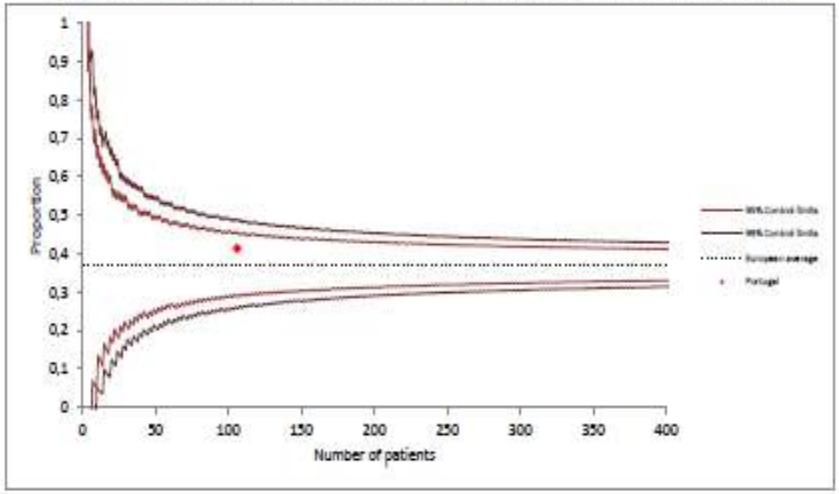
Age-adjusted average height Z-score



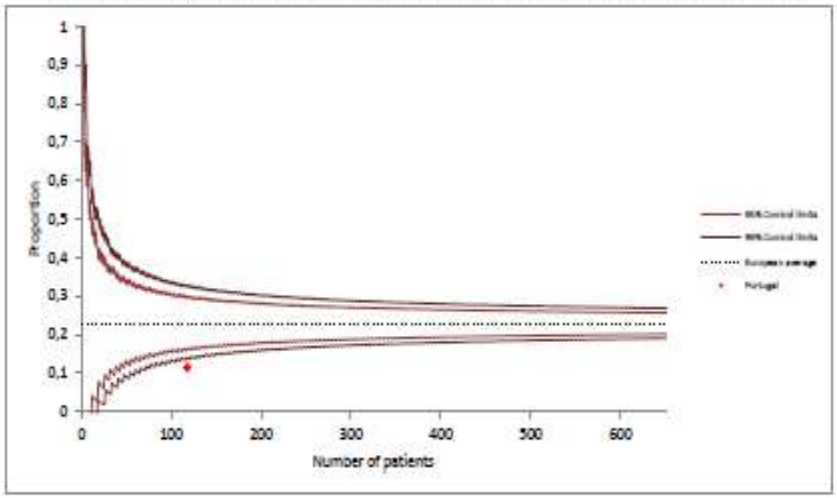
Benchmarking Report

Hypercholesterolemia

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

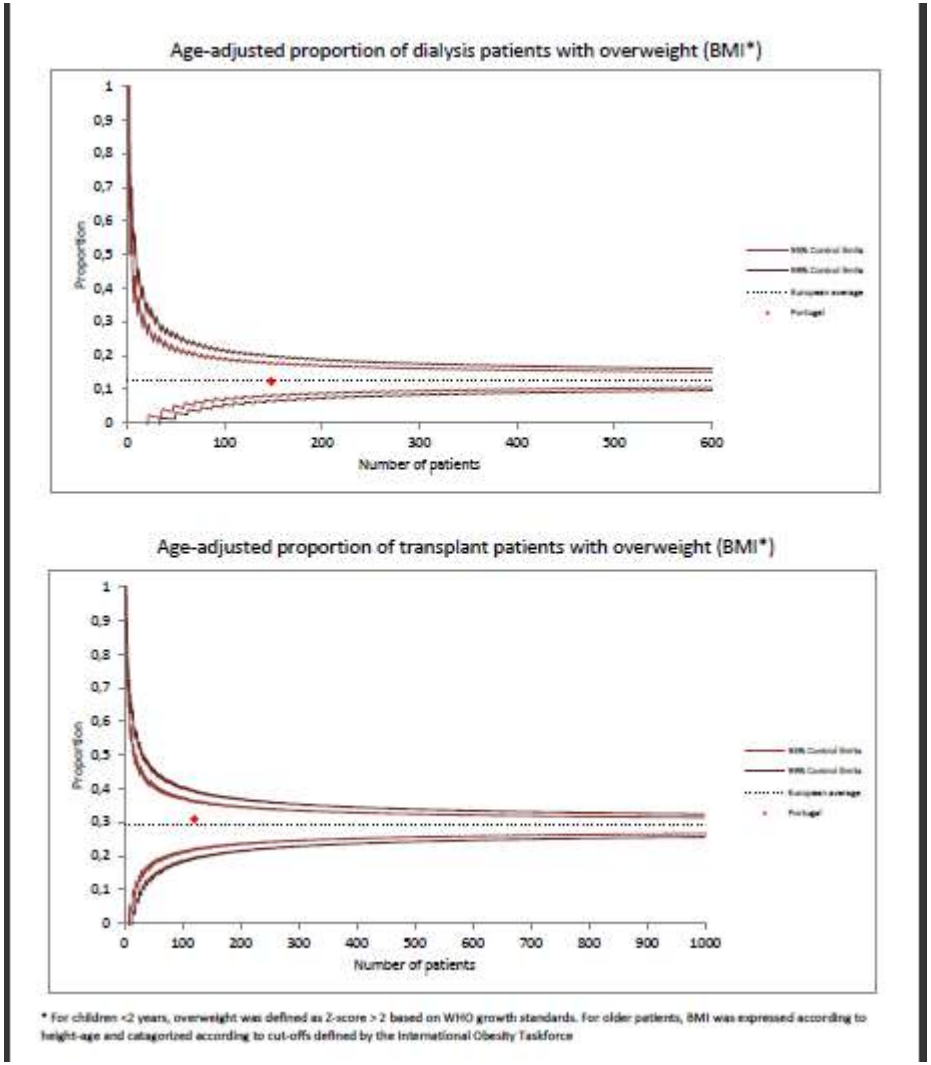


Age-adjusted proportion of transplant patients with hypercholesterolemia (>200 mg/dl)



Benchmarking Report

Age-adjusted proportion of patients with overweight



Ponto vermelho Portugal

Publicações da ESPN/ERA-EDTA
(coautoria nefrologistas pediátricos portugueses

1. *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.*

2. *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, Schae-fer F; NDT 2013; 0:1-10*

3. ***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 theESPN/ERA–EDTA registry. Pediatr Nephrol. 2014 Jul 21.*

4. *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)

4. ***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 M[1], Busutti M[1], van Stralen KJ[2], Jager KJ[1], Baiko S[1], Bakkaloğlu S[1], Battelino N[1], Gaydarova M[1], Gianoglio B[1], Parvex P[1], **Gomes C**[1], Heaf JG[1], Podracka L[1], Kuzmanovska D[1], Molchanova MS[1], Pankratenko TE[1], Papachristou F[1], Reusz G[1], Sanahuja MJ[1], Shroff R[1], Groothoff JW[1], Schaefer F[1], Verrina E. ***Clin J Am Soc Nephrol.*** *2015 May 7;10(5):767-75. doi: 10.2215/CJN.06200614.*

5. ***.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 M[1], Bonthuis M[2], Sahpazova E[3], Mencarelli F[4], Spasojević B[5], Reusz G[6], **Caldas-Afonso A**[7], Bjerre A[8], Baiko S[9], Vondrak K[10], Molchanova EA[11], Kolvek G[12], Zaikova N[13], Böhm M[14], Ariceta G[15], Jager KJ[2], Schaefer F[16], van Stralen KJ[2], Groothoff JW[1]. ***Nephrol Dial Transplant.*** *2015 Apr 28. pii: gfv105.*

6. ***IInfants 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.*

Publicações da ESPN/ERA-EDTA
(coautoria de nefrologistas portugueses)

7. ***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, Zagozdzon I, Harambat J, Jager KJ, Groothoff JW, van Stralen KJ.* ***Lancet.****2017May; 389(10084) :2128-2137.*

8. ***Growth patterns after kidney transplantation in European children over the past 25 years: An ESPN/ERA-EDTA Registry study..*** *Bonthuis M, Groothoff JW, Ariceta G, Baiko S, Battelino N, Bjerre A, Cransberg K, Kolvek G, Maxwell H, Miteva P, Molchanova MS, Neuhaus TJ, Pape L, Reusz G, Rousset-Rouviere C, Sandes AR, Topaloglu R, van Dyck M, Ylinen E, Zagozdzon I, Jager KJ, Harambat J. Transplantation 2020; 104(1):137-144.*