



ERA Registry report 2023

Vianda Stel and Alberto Ortiz

ERA Registry

1. Output 2023
2. Cost vs budget

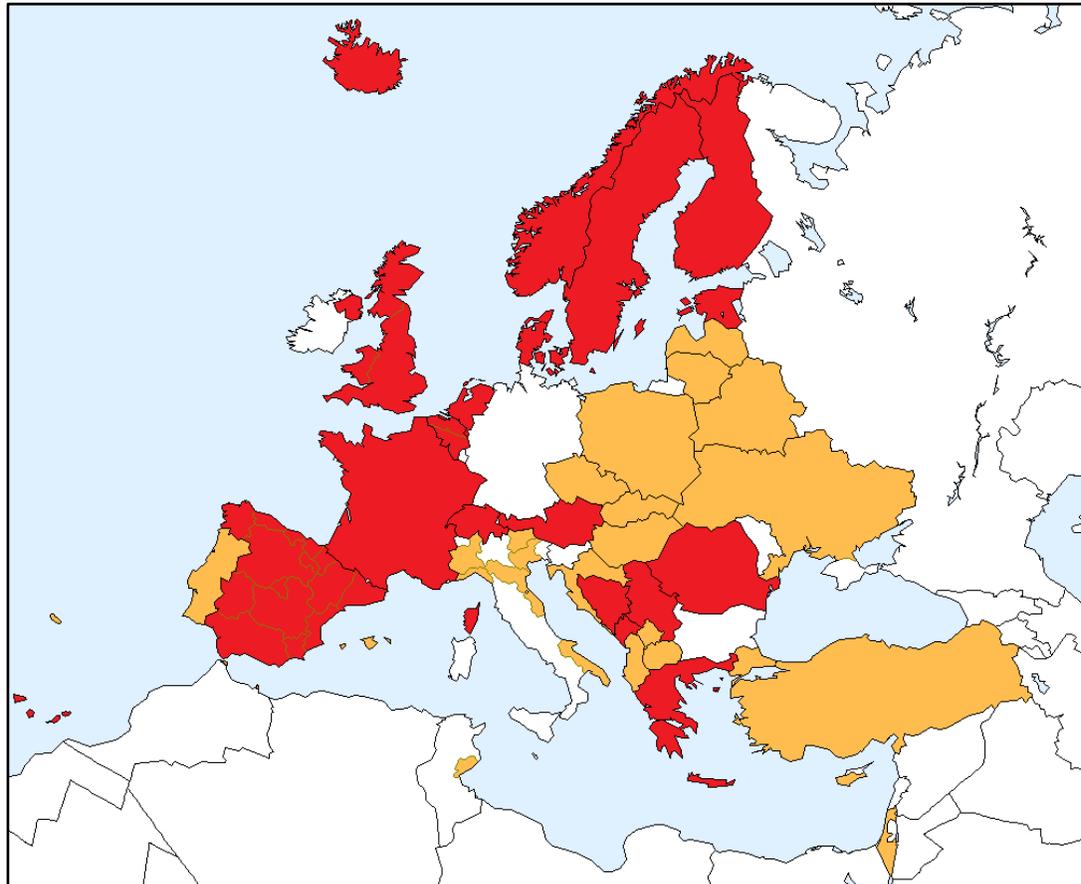
ESPN/ERA Registry

1. Output 2023
2. Cost vs budget

Summary of Achievements of the Registry over 2023

- 1 Expansion of the ERA Registry database with waitlist, donor and transplant variables
 - 2 Exploring the feasibility and relevance of an ERA-CKD Registry
 - 3 Update of the ERA coding systems for primary renal diseases and causes of death
 - 4 Further extension of the ERA Registry Collaborative Research Network by setting up and participate in special studies
 - 5 Continuation of EQUAL
 - 6 22 papers published and 6 in press
 - 7 1 PhD thesis entitled '*Treatment modality choices for end-stage kidney disease in Europe*'
 - 8 Organization and teaching of the ERA '*Introductory course to Epidemiology*'
 - 9 4 research fellows at the Registry
 - 10 Starting 2 series of educational papers in *NDT and CKJ*
 - 11 1 ERA Registry Annual Report
 - 12 1 newsletter, 1 Registry symposium, online meetings with Registry Committee members and renal representatives to discuss ongoing studies
 - 13 Serve as a member of the statistical editorial board of CKJ, the editorial board of NDT and as members of the Scientific Committee 60th ERA Congress in Milan
 - 14 A positive evaluation by the ERA Registry Committee
 - 15 Renewal of certification for NEN-EN ISO 9001:2015 up to 2025 and obtaining certification for ISO 27001:2013 up to 2022
-

National and regional renal registries that contributed data to the 2021 ERA Registry Annual Report



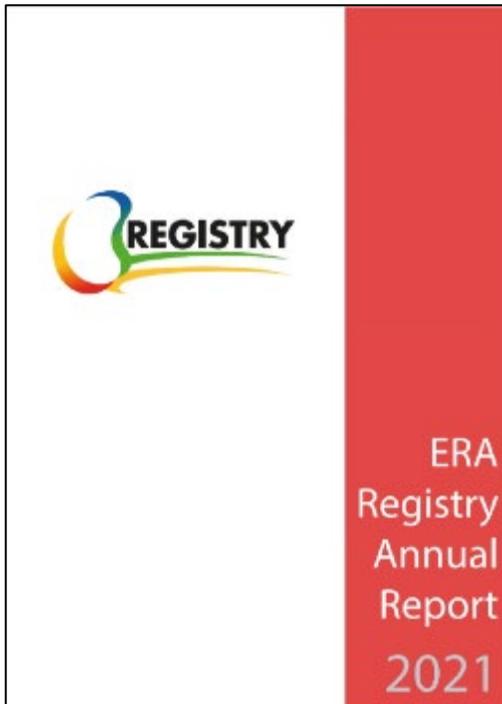
-  Renal registries contributing with individual patient data
-  Renal registries contributing with aggregated data

Summary in CKJ

Summary in NDT

- Since 2009 (annually)
- Focus on comparison between countries

- Since 2024 (annually)
- Focus on comparison between Europe and US



ERA Clinical Kidney Journal

The ERA Registry Annual Report 2021: a summary

This summary of the ERA Registry Annual Report 2021 provides an update on the epidemiology of kidney replacement therapy (KRT) for patients with end-stage kidney disease in Europe and countries bordering the Mediterranean Sea.

	Results	
	Incident KRT	Prevalent KRT
N (pmp), unadjusted	76,240 (145 pmp)	554,797 (1,040 pmp)
Age, median years	68.2	64.0
Proportion male	64%	62%
Most common PRD	Diabetes (22%)	Glomerulonephritis/sclerosis and diabetes (both 16%)

Methods
ERA Registry on KRT
54 registries, 36 countries (533 million people covered)
Individual patient data: 35
Aggregated data: 19

Outcomes:

- KRT incidence and prevalence per million population (pmp)
- Kidney transplantation rates
- Survival probabilities
- Expected remaining lifetimes
- Comparisons across treatment modalities

The overall unadjusted kidney transplantation rate was 37 pmp, with differences in transplants from deceased donors (24 pmp) and living donors (12 pmp).

Life expectancy was 65% and 68% shorter for males and females on dialysis, and 40% and 43% shorter for males and females living with a functioning graft compared to the general population.

Treatment modality by age

Age Group	Tx	PD	HD
0-19	77	14	8
20-44	66	30	3
45-64	59	37	4
65-74	43	52	5
75+	20	73	6

Conclusion: In 2021, the incidence of KRT in Europe was 145 pmp and the prevalence was 1,040 pmp. Life expectancy was substantially shorter for patients on dialysis and living with a functioning graft.

Boerstra, B.A.
Clinical Kidney Journal (2021)
b.a.boerstra@amsterdamc.nl
@CKJsocial

ERA ndt

A comparison of the epidemiology of kidney replacement therapy between Europe and the United States: 2021 data of the ERA Registry and the USRDS

The aim of this study was to compare the epidemiology of kidney replacement therapy (KRT) in 2021 between Europe and the United States (US), focusing on the distribution by treatment modality.

Methods
Data were obtained from the latest ERA Registry and USRDS Annual Reports.

Results

Incidence of KRT in 2021 by treatment modality

Treatment Modality	ERA Registry	USRDS
Haemodialysis	119	20
Peritoneal dialysis	6	52
Kidney transplantation	343	13

Prevalence of KRT in 2021 by treatment modality

Treatment Modality	ERA Registry	USRDS
Haemodialysis	566	561
Peritoneal dialysis	1432	759
Kidney transplantation	599	59

Mortality on KRT in 2021 by treatment modality

Treatment Modality	ERA Registry	USRDS
Haemodialysis	161	131
Peritoneal dialysis	85	165
Kidney transplantation	207	53

Kidney transplantation rate in 2021

Donor Type	ERA Registry	USRDS
Deceased donor	33	9
Living donor	18	59

Despite the much higher KRT incidence in the US, a similar proportion of patients started with haemodialysis (~83%), peritoneal dialysis (~13%), or underwent pre-emptive kidney transplantation (~4%).

Despite the higher kidney transplantation rate in the US, approximately half of all European prevalent patients were living with a functioning graft, while in the US this was one third.

The US had a much higher KRT incidence, KRT prevalence, kidney transplantation rate and KRT mortality compared with Europe.

Stel, VS. et al.
Nephrol Dial Transplant (2024) xx: xxx-xxx
@NDTSocial

Annual report is supplement of CKJ paper

1. Preparing European Nephrology for the next pandemic: lessons from the ERACODA collaboration. Vart P. **NDT**
2. Outcomes of COVID-19 in peritoneal dialysis patients. Abrahams A. **Perit Dial Int**
3. Associations of longitudinal height and weight with clinical outcomes in pediatric KRT. Bonthuis M. **Ped Nephrol**
4. National health policies and strategies for addressing CKD: data from the Global Kidney Health Atlas. Neuen B. **PLOS Global Public Health**
5. Defining measures of kidney function in observational studies using routine health care data. Carrero JJ. **NDT**
6. Increasing numbers and improved overall survival of patients on KRT over the last decade in Europe. Huijben JA. **NDT**
7. The strengths and complexities of European registries concerning paediatric kidney transplantation health care. Oomen L. **Front Ped**
8. Involving patients in treatment decisions, disease management and research for end-stage kidney disease. Jager KJ. **CKJ**
9. The ERA Registry Annual Report 2020: a summary. Astley ME. **CKJ**
10. Decreasing incidence of dialysis in older patients in the Netherlands as compared with other European countries. van Oevelen M. **CKJ**
11. Serum Potassium and Risk of Death or Kidney Replacement Therapy in Older People with CKD Stage 4-5: 8-Year Follow-up. De Rooij E. **AJKD**
12. Disparities in treatment and outcome of KRT in children with comorbidities. Schild RS. **CKJ**
13. Factors influencing kidney transplantation rates: a study from the ERA Registry. Boenink R. **NDT**
14. Trends in kidney transplantation rate across Europe. Boenink R. **NDT**
15. Clinical and patient reported trajectories at end-of-life in older patients with advanced CKD. Chesnaye NC. **NDT**
16. The impact of sex on the risk of cardiovascular events in older adults with advanced chronic kidney disease. Astley ME. **CKJ**
17. Association between CKD-MBD and mortality in older patients with advanced CKD - results from the EQUAL study. Magagnoli L. **NDT**
18. Regional Variation in Hemoglobin Distribution Among Individuals With CKD: the ISN International Network of CKD Cohorts. Canney M. **KI Reports**
19. Protein biomarkers and MACE. Hayward S. **Kidn Med**
20. A new methodological series in CKJ. Zoccali C. **CKJ**
21. European CKD registries for children not on KRT: tools for improving health systems and patient-centred outcomes. Bakkaloğlu SA. **CKJ**
22. The long-term benefits of early intensive therapy in chronic diseases-the legacy effect. Zoccali C. **CKJ**

1. The ERA Registry Annual Report 2021: a summary. Boerstra B **CKJ**
2. A comparison of the epidemiology of KRT between Europe and the United States: 2021 data Stel VS **NDT**
3. International comparison and time trends of first kidney transplant recipient characteristics across Europe. Boenink R **NDT**
4. The long-term effect of a lung-ultrasound intervention on outcomes in dialysis patients. Torino C **NDT**
5. Incidence and outcome of KRT for ESKD due to primary glomerulonephritis in Europe. Abd Delhafeez S **NDT**
6. Changes in the epidemiology of KRT across Europe in 2020 – the first year of the COVID-19 pandemic. Kramer A **NDT**



ERA Registry cost vs budget 2023

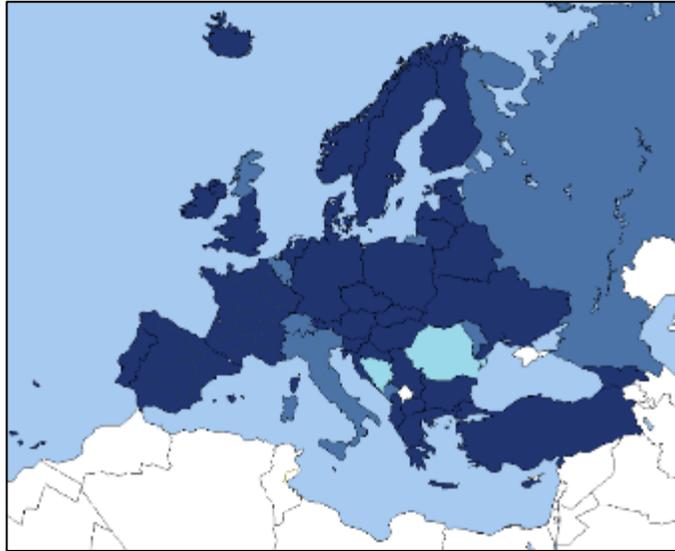
Budget item	Average fte	2023		
		Cost As per 25-3-2024	Budget	Surplus
Staff incl overhead and legal labor cost	7.08	688,302	691,273	2,971
Hardware/software (incl SAS)/servers		6,982	8,000	
Office		226	1,500	
Travel/congress		12,851	15,000	
Miscellaneous		11,474	8,000	
EQUAL central costs		0	8,000	
Subtotal other costs		31,533	40,500	8,967
ISN payment		-4,548		4,548
Total		715,287	731,773	16,486

- (1) Current contract surplus for 2023 up to € 16,486; Proposal: up to €16,486 to be returned to ERA
- (2) Contract surplus for 2020 up to € 71.234 will be used to set up the CKD Registry once the CKD Registry is running, as approved by the ERA Council
- (3) Installments: ERA has paid all 2023 installments to AMC (€731,773)

- In 2023, Marjolein Bonthuis is appointed (0.67 fte) as postdoc; this was needed to accommodate Kitty Jager's departure. In 2024, Kitty Jager is not on Registry's payroll anymore.
- Miscellaneous includes publication costs
- ISN paid for the participation with EQUAL in a collaborative project on 'Regional Variation in Hemoglobin Distribution Among Individuals With CKD: the ISN International Network of CKD Cohorts (DOI: <https://doi.org/10.1016/j.ekir.2023.07.032>)



ESPN/ERA Registry



- Provided (extended) data in 2023
- Provided data prior to 2023
- Provided data via the ERA Registry

Total 2023:
34 countries
Data on > 28,000 children

Published papers 2023

- | | |
|---|------------------------|
| 1 Anthropometry and clinical outcomes | <i>Pediatr Nephrol</i> |
| 2 Comorbidities in children at KRT initiation | <i>Clin Kidney J</i> |
| 3 European CKD registries for children | <i>Clin Kidney J</i> |



ERA/ESPN Registry cost vs budget 2023

Budget item	Average fte	2023		
		Cost (as per 25-03-2024)	Budget	Surplus
Total staff incl overhead and legal labour costs	1.22	88,366	100,891	
Hardware and SAS software		2,402	1,200	
Office		0	300	
Travel		2,840	1,100	
Miscellaneous		2,196	2,000	
Total		95,803	105,491	9,688

- (1) The surplus up to € 9,688 to be paid back to ERA (€ 7,266) and to ESPN (€ 2,422)
- (2) All 2023 installments have been paid by ERA to AMC (€ 79,118) and by ESPN to AMC (€ 26,373)